UNIVERSITY OF LIVERPOOL

The differences in being different: a narrative analysis of the nature of epilepsy in adults and its problems

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy

By

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AUTHOR'S DECLARATION

This thesis is the result of my own work. The material contained in this thesis has not been presented, nor is currently being presented, either in part or wholly for any other degree qualification.

I designed this research in conjunction with my supervisors and was solely responsible for data collection, analysis and write-up.

ABSTRACT

Epilepsy is not just a medical condition but a social label; successful clinical treatment is therefore only one aspect of epilepsy management. However, the particular ways in which features of an individual's background and clinical condition influence the impact that epilepsy has on them is not yet fully understood. The voice of the individual living with epilepsy is at the core of this study. Drawing upon research on illness narratives, this qualitative study is embedded in the perspective that knowledge construction relies upon the socially crafted tool of language which facilitates a broader range of perspectives and promotes greater subjectivity. I draw upon the illness stories of fourteen adults with epilepsy to explore how the condition impacts directly or indirectly on daily living and life trajectories, and to re-present the diverse nature and meaning of having epilepsy, including its stigma potential. I conducted in-depth interviews with seven male and seven female participants attending epilepsy outpatient clinics. Interview transcripts were subjected to paradigmatic and narrative analysis in order to examine thematic similarities and differences. Participant stories were identified using Mishler's theoretical model of 'Core Narrative'. Narrative encounters with participants reflected both their recent and more distant experiences of epilepsy. What emerged from the stories was a discourse of disruption and difference, with epilepsy often imposing barriers to daily living and to maintaining a positive sense of self as participants searched for meaning. While the stories told were uniquely individual, collectively a dominant *plot* was seen to emerge. For the adults with epilepsy in this study the plot takes the individual from a beginning of 'discovery and diagnosis', through the process of 'searching for a cause', 'negotiating risk and uncertainty', and, 'striving for control'. As individuals communicate what is significant to them, attention to patient stories provides insight into how experience is constructed and evolves over time. Due consideration of such stories by health professionals can offer direction in which intervention(s) can occur to ensure the interests and needs of the individual with epilepsy are holistically considered and met.

DEDICATION

This work is dedicated to my daughter Rebecca Snape,

and

in loving memory of my mum and dad, Roy and Evelyn Wilkinson.

ACKNOWLEDGEMENTS

Firstly, I should like to thank my daughter Rebecca, my grandson Ben (whose wit and humour kept a smile on my face) and my friends for their continuous and unconditional support; without their encouragement this work would not have been possible.

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Finally and most importantly I would like to thank the men and woman who took part in this study; selflessly speaking to me about their life experiences with epilepsy and dedicating time and commitment to the construction of their stories. Your stories have been the inspiration for this research which would not have been possible without you – ***thank you***.

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GLOSSARY OF TERMS

Scope

This glossary provides an overview of definitions, not provided in text, for the terms associated with the discourse(s) around epilepsy, as they appear within this thesis. The terms, both lay and professional, are cited alphabetically below:

Absence seizure / absences: In the past, sometimes referred to as petit mal seizures. The person looks blank for a few seconds and may not respond when spoken to or realise they have had a seizure. Most absence seizures last 10 seconds or less and can occur repeatedly; often being mistaken for daydreaming. There is no postictal state, but the person usually lacks awareness of what occurs during the seizure.

Auras / or warnings as they are sometimes called: Some people experience a particular smell / sound / feeling before a seizure starts. This is known as an aura and it is itself a focal seizure.

Complex partial seizure: Loss of consciousness distinguishes complex partial seizures from simple partial seizures. While unconscious, the patient may have a 'vacant' or 'frightened' look and may have signs and symptoms of a simple partial seizure. Automatisms may occur during unconsciousness such as, for example: chewing, increased salivation, facial expressions of fear, bewilderment, discomfort, tranquillity, laughter, crying, repetitive movements of the hands, fingers, sexual gestures, wandering, running, repeated short phrases or swearing. Patients who have had complex partial seizures over a period of years may develop *drop attacks.* When this occurs, they lose postural tone and fall with the sudden onset of unconsciousness.

Epilepsy Action: This is the largest membership organisation in the United Kingdom for people affected by epilepsy.

Epileptic: Although the term ‘epileptic’ is sometimes used it is important to look at the person before the medical condition, therefore it is more appropriate to say ‘a person with epilepsy'.

Epileptology: This is a branch of neurology which focuses specifically on the study and treatment of epilepsy.

Febrile seizures: Occur in small children and are caused by high fever. Children may experience another febrile seizure, but only a few develop epilepsy.

Fit: Although the term ‘seizure' or ‘epileptic seizure' is preferred by many people, some people with epilepsy choose to use the word ‘fit’.

Gelastic seizures: Gelastic epilepsy is a type of epilepsy characterised by laughter. Gelastikos is the Greek word for laughter. Gelastic epilepsy is slightly more common in boys than in girls. It is, however, very rare and of every 1,000 children with epilepsy, only one or at the very most two, children will have gelastic epilepsy.

Generalised seizures: At the onset, seizure activity occurs simultaneously in large areas of the brain, often in both hemispheres. Seizures can be convulsive or non-convulsive. The two most common types are tonic-clonic and absence**.**

Grand Mal seizures: A term previously used to describe types of seizure. There are many types of seizures so this term is too general and, in medical terms, is now considered outdated.

Idiopathic epilepsies: Idiopathic epilepsies are not associated with brain lesions or mental impairment, however genetic factors are important and epilepsy onset is usually age related. Idiopathic epilepsies tend to be self-limiting and respond to anti-epileptic drug treatment.

Jacksonian seizures: A type of simple partial seizure characterized by abnormal movements that begin in one group of muscles and progress to adjacent groups of muscles

(motor seizure). These movements reflect the march of seizure activity arising from the pre-rolandic gyrus area of the brain through the brain's motor cortex.

Juvenile myoclonic epilepsy: Approximately 5 percent of people with epilepsy have juvenile myoclonic epilepsy. The condition begins in childhood or adolescence and lasts into adulthood. The most common type of seizure in people with this condition is myoclonic seizures, which cause rapid, uncontrolled muscle jerks. People with this condition may also have generalized tonic-clonic seizures (grand mal seizures), which cause muscle rigidity, convulsions, and loss of consciousness. Although seizures can happen at any time, they occur most commonly in the morning, shortly after awakening. Seizures can be triggered by a lack of sleep, extreme tiredness, or alcohol consumption.

Myoclonic seizures: Rhythmic muscle jerks that can affect part of / the whole body and can be strong enough to throw the person to the ground. These seizures are so brief that they may go unnoticed. They involve sudden muscle contractions that occur much more rapidly than clonic activity and are often confused with tics. Myoclonic seizures occur at all ages and are associated with epileptic syndromes such as West syndrome and Lennox-Gastaut syndrome.

Partial (focal, local): The site of origin is a localised or discreet area in one hemisphere of the brain. The two most common types of partial seizure are simple partial and complex partial.

Peti Mal seizures: A term previously used to describe types of seizure. There are many types of seizures so this term is too general and, in medical terms, is now considered outdated.

Resective surgery: This is the most common form of surgical treatment for uncontrolled seizures. Resective surgery is a type of epilepsy operation in which the area of the brain responsible for seizures is surgically removed. The brain is comprised of four lobes, called the frontal, temporal, parietal and occipital lobes. Seizures most often arise from one or both temporal lobes.

Seizure: This can be defined as abnormal, uncontrolled electrical activity in brain cells. Normally, nerve transmission in the brain occurs in an orderly way, allowing a smooth flow of electrical activity. Improper concentration of salts within the cell and over activity of either type of neurotransmitter can disrupt orderly nerve cell transmission and trigger seizure activity.

Symptomatic epilepsies: Those in which seizures are the consequence of an identifiable lesion or other physical or metabolic cause.

The epilepsies: Epilepsy is not a single condition; rather many different types of epilepsy. Hence, use of the collective term 'the epilepsies'. Epilepsy can start at different times for different people. The different types of epilepsy can produce different signs and symptoms.

Tonic–clonic seizures: In the past, sometimes referred to as grand mal seizures. There is loss of consciousness during the seizure. The tonic phase, consisting of increased muscle tone (rigidity), is followed by the clonic phase, which involves jerking of the extremities. Autonomic symptoms including, for example: increased blood pressure and heart rate, increased bladder pressure, flushing, sweating, increased salivation, increased bronchial secretion and apnoea may also be present**.**

Definitions provided in this glossary of terms have been drawn from the following on-line information sites, accessed on 8th August, 2014:

www.epilepsy.org.uk

www.epilepsysociety.org.uk/sites/default/files/attachments/Chapter01Neligan.pdf

http://ghr.nlm.nih.gov/condition/juvenile-myoclonic-epilepsy

www.mdguidelines.com/jacksonian-seizure

http://neurology.stanford.edu/epilepsy/patientcare/videos/e_24.html

RESEARCH RELATED OUTPUTS

Publications

Jacoby, A., **Snape, D.**, Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. *Lancet Neurology*. **4**:171-78.

Snape, D., Jacoby, A., Baker, G.A. (2005). Stigma and Social Issues In: *Atlas: Epilepsy Care in the World*. WHO p78.

Jacoby, A., **Snape, D.,** Baker, G.A. (2008). Social Aspects: Epilepsy Stigma and Quality of Life. In J. Engel, T.A. Pedley eds. *Epilepsy: A comprehensive Text Book.* 2nd Edition. New York: Lippincott Raven. Chapter 216. p2229-2236.

Fernandes P., **Snape D.**, Roy G., Beran R.G., Jacoby A. (2011). Epilepsy stigma: What do we know and where next? *Epilepsy and Behavior.* **22**:55-62.

Platform presentations

Snape, D. Chronic Illness, experience and context: Methodological diversity in qualitative health research. Symposium 3. The Royal College of Nursing International Nursing Research Conference. Liverpool, UK. 8th-11th April, 2008.

Snape, D. *Living with epilepsy: a narrative analysis.* The PRISM Conference, Liverpool, UK. 2008.

Snape, D. Why Should We Listen To The Stories Told By People With Epilepsy? The PRISM Conference, Manchester, UK. 2009.

Poster presentations

Snape D. *Epilepsy Narratives: The difference in being different.* 7th European Conference on Epileptology, Helsinki, Finland. 2-6th July, 2006.

Snape D. *Epilepsy Narratives: The difference in being different.* 10th European Congress on Epilepsy and Society, Copenhagen, Denmark. 2nd-4th August, 2006.

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International Bureau for Epilepsy Travel Scholarship

2006: International Bureau for Epilepsy Research Travel Scholarship **£ 250**

CHAPTER ONE

1. Introduction to the study

In this chapter I set out the rationale for my study and present a brief synopsis of the contents of this thesis.

1.1. Study rationale

> *"We are, in an important sense, the stories of our lives. How sickness affects us depends on how sickness alters those stories"*. (Brody, 1987, p182).

The voice of the individual living with epilepsy is at the core of this study. Embedded in the postmodern perspective that knowledge construction relies upon the socially crafted tool of language, which facilitates a broader range of perspectives and promotes greater subjectivity (Clifford, 1988; Atkinson, 1990), I draw upon the narratives of fourteen participants to explore how epilepsy impacts directly or indirectly on daily living and life trajectories, and to represent the heterogeneity of the *meaning* of having epilepsy. Although research on illness narratives exists, the narratives of people with epilepsy, with few notable exceptions, are scarce. Consequently, I argue, the potential for healthcare professionals and others to learn from the unique stories and experiences of people with epilepsy has also been neglected.

Alcauskas and Charon (2008) call for the introduction of narrative approaches in the treatment of neurological disorders. They argue that neurology in particular would benefit from such an approach because diagnostic technology aside, heavy reliance is placed upon patient history as a means to informing the diagnostic process. Epilepsy[1] provides healthcare professionals with a case in point, as it is a condition that finds itself embedded in multiple medical, social, and cultural discourses (Tempkin, 1971). Thus, the successful treatment of epilepsy needs to extend beyond seizure control - as important as this is - to enabling those with the condition to participate in, and be accepted by, society (Vaccarella, 2011).

[1] Now referred to as 'The Epilepsies' (NICE, 2012).

Within Western contemporary medicine, epilepsy represents a common neurological condition, characterised by recurring seizures. Technological and therapeutic advancements in the field of science and medicine, and the increased effectiveness of anti-epileptic drug regimens have served to position epilepsy, with in a biomedical framework, as a relatively benign condition with an excellent clinical outcome (Sander & Sillanpaa, 1997). This prevailing biomedical discourse with its emphasis on 'treat the seizures' provides the dominant framework (as outlined in the National Institute for Clinical Excellence (NICE) epilepsy guidelines) in practice generally (NICE, 2012) and was the dominant approach to medical encounters of participants in the present study.

The supposition of this medical model is that seizure control would, in itself, positively impact upon an individuals' quality of life. I argue that the narratives of people with epilepsy provide a mechanism for challenging this received wisdom. For example, the comment *"It's not just the actual seizures; it's living with epilepsy"* offered by Brenda, one of my participants, poses the question how useful is practice which affords primacy to prioritising biological and physical dysfunction? Such practice, I argue, highlights the disparity between the homogeneity of the treatment approach and the heterogeneity of lived experience, as Bishop and Allen argue:

> "*the impact and consequences of epilepsy cannot always be understood as resulting directly or logically from the occurrence of seizures".* (Bishop & Allen, 2003, p227).

Mismatches between the medical model of *'treat the seizures'* and the lay model of *'learning to manage a life with epilepsy'* not only negatively impact on patient expectations and concerns, but also on clinicians' knowledge and interpretations of patients' concerns. As a consequence this scenario has the potential to negatively impact on the outcomes of clinician-patient consultations (Vaccarella, 2011). Anne Fadiman's (1997) chronicle -*The Spirit Catches You and You Fall Down* – serves to highlight this issue by contrasting the perspectives of the family of a child with epilepsy and her formal caregivers. Here, Fadiman examined the tensions and conflict between western medicine and Hmong traditions in the treatment of epilepsy and, in so doing, aptly demonstrated the importance of the need for clinicians to be sensitive to potential differences in medical and lay perspectives.

In this regard, I argue the importance of the illness narrative: medical professionals must become versed in patient narratives of *'a life lived with epilepsy'*. For such narratives hold the potential to alert healthcare professionals to the wider landscape of patient concerns

and beliefs, and to the role of societal and cultural narratives in affecting individual experience; including for example, popular interpretations of treatments and lay explanations of epilepsy that influence patients' treatment choices. Becoming acquainted with the patient's epilepsy narrative not only assists with diagnosis, but will also assist in proposing a treatment programme that is patient-centred (NICE, 2012).

1.2. Research summary and aims

Epilepsy is one of the most prevalent neurological disorders, affecting people in every country throughout the world. Around 50 million people in the world are reported to have epilepsy at any one time (WHO, 2012). It is the most serious and the most common neurological condition seen in primary care (Lambert & Bird, 2001). The Joint Epilepsy Council (JEC, 2011), report approximately 1 in 103 people in the United Kingdom have epilepsy – a prevalence of 9.7 per 1,000 (0.97%). There are an estimated 0.51/1,000 newly treated cases per year, equating to 600,000 patents with epilepsy in the United Kingdom today (Office for National Statistics, 2011). This is equivalent to approximately 32,000 new cases diagnosed per year – equivalent to approximately 87 new cases each day of the year.

Epilepsy is a tendency to have recurrent seizures; affecting anyone at any age and from any walk of life. Being diagnosed with epilepsy not only involves learning to deal with the physical impact of seizures, but also learning to cope with the associated, harmful social and psychosocial consequences, which are not directly related to the actual disease process (Engel, 2000). The limitations imposed by statute, prejudice, fear and lack of understanding have major implications for social functioning and life choices. Not surprisingly these challenges can impact upon the person's experience and the narrative they construct. This new experience and all it entails is easier for some individuals to cope with than for others (Baker and Jacoby, 2000) and as such can impact profoundly upon not only how people with epilepsy live their lives, but how they and others narrate their identity.

Through hearing the narratives of people living with epilepsy, the present study aims to:

- Better understand the experience(s) of those diagnosed with the condition; and,
- Consider the ways in which these narratives are constructed and articulated to others and how the narratives are influenced by others

The purpose of this research is to promote holism, encourage empathy and enhance understanding between patients and healthcare professions of this life-changing

experience, with the view to promoting a patient-centred epilepsy healthcare agenda (NICE, 2012).

1.3. Research questions

The primary research question is:

- How do individuals living with epilepsy describe their experiences?

Secondary research questions derive from how these narratives account for:

- How individuals come to interpret what having epilepsy means;
- How individuals see themselves as a consequence of this interpretation, and,
- What impact this interpretation has on the way individuals interact with others

1.4. The literature

A systematic search and review of the literature in relation to this work has been regularly updated to present day. My purpose throughout this endeavour was to identify primary research and reviews in relation to various 'bodies of literature' relevant to the study of epilepsy, stigma, chronic illness, biographical disruption, postmodernism, social constructionism, and qualitative research and narrative research methods. References for the various literature reviews were identified with the aid of a search strategy and the application of search terms; full details of the literature search strategy, including search terms and combinations, inclusion and exclusion criteria and data resources, are available in a separate document[2]. The use of a search strategy enabled the conduct of systematic, reproducible, computerised searches of relevant journals, databases and websites. In addition, secondary references that met the inclusion and exclusion criteria were identified from retrieved articles. To reduce the effects of a biased review, grey literature resources were also accessed for relevant information related to each of the searches undertaken. 'Experts in the field' networks, including clinical and non-clinical academics, were contacted as a means of identifying related information including conference papers, unpublished and ongoing research.

[2] See Appendix 1: Literature Search Strategy

In reviewing and critiquing these various bodies of evidence I chose not to present them in a single 'literature review' chapter. My rationale for this decision was underpinned by my epistemological positioning which enabled me to define literature that dealt with very distinct areas of thinking which I felt did not sit comfortably next to each other within a single chapter; rather I wanted to link the literature to the key concepts as they were being discussed. The position from which I came to this research - postmodernism and social constructionism – places discourse as being co-constructed and open to multiple interpretations. I therefore chose to contextualise the relevant literature, as a means to highlight the link between philosophy and research method and to explore its significance to specific topics and issues under discussion. This was achieved by conducting two focused reviews around epilepsy which contained various bodies of literature (as identified above). The first review focused on the sociology of chronic illness, biographical disruption and reconstruction, coping, and, the potential of illness narratives to elicit stories of experience. These various theoretical debates have value in informing what goes on when a person has epilepsy and were used to inform my epistemological and methodological arguments, as discussed in Chapter Two (see also section 1.5 below). The second review focused on epilepsy as a medical condition and a social phenomenon, including as stigma; my intension here was to align the phenomenon of epilepsy to its historical, cultural, medical and social milieu and to use this evidence to support my argument that the experience of epilepsy is much greater than its symptoms; these discussions I articulate in Chapter Three (see also section 1.6 below). In separating the literature in this way across chapters two and three I have endeavoured to place my observations and arguments in context.

1.5. Narrative inquiry: linking philosophy and method

In Chapter Two I set out my epistemological and methodological arguments and offer a critique of medical discourse, with a view to revealing an alternative discourse - that of the individual living with epilepsy - through the elicitation of patient narratives. I argue this alternative discourse has the potential to provide new ways of understanding the experience of epilepsy by illuminating points of tension in healthcare encounters and in daily living, offering directions in which interventions can address this tension and ensure interests and needs of the individual with epilepsy are met Previous research on how individuals adjust to chronic illness has identified narrative as a mechanism for both facilitating the illumination of these issues and for enabling individuals to re-evaluate and

re-construct coping with contingencies of everyday life and sense of self. A review of the pertinent literature is presented.

The central tenet of narrative inquiry is attention to the potential of stories to give meaning to people's lives, and the treatment of data as stories. It is one of many kinds of research gathered under the umbrella of qualitative research approaches (Polkinghorne, 1995); however, it is an approach devoid of any single heritage or methodology. Those who practice it draw upon diverse sources of influence and often use an amalgam of methods. In the final part of this chapter therefore, I discuss the theoretical influences that have guided my own narrative practice within the context of this study; and outline the study methods and sample.

1.6. Constructing epilepsy: the importance of time, place and context

In Chapter Three the interdiscursive position of epilepsy as a medical, social and symbolic phenomenon is brought to the fore. Following a review of pertinent literature, I outline the numerous constructions of epilepsy, including: moral constructions of epilepsy, biomedical constructions of epilepsy and constructions of epilepsy as a stigmatising illness. My purpose in presenting this discussion is to illustrate the varied ways in which the phenomenon of epilepsy has been understood and to demonstrate how language, meaning and power relations (see for example, Foucault 1974; Foucault & Gordon, 1980) have the potential to shape social organisations and relationships and the way in which this condition is known and experienced. By mapping epilepsy across its historical, cultural, medical and social contexts I make clear that the experience of epilepsy is much greater than its symptoms and more complex than its treatment. In concluding this chapter I advocate narrative inquiry as a research approach. Stories, as told by those with the condition, provide a mechanism for examining epilepsy from the perspective of the sufferer; a view in which the human subject rather than the pathology is the central character.

1.7. Organisation of analysis

In the analytic chapters that follow (chapters four, five, six and seven), I offer an analysis of how people with epilepsy described their experiences; coped with and drew meaning from those experiences; and, how their understanding of their epilepsy affected their sense of self. The data are rich and as such presented me with the challenge of deciding how best to

maintain the integrity of individual, contextualised accounts whilst at the same time structuring a coherent story for the reader. In line with my philosophical approach I begin the analysis with an introduction to the 'story tellers'. These accounts are third person accounts, reflecting my own interpretation of my participants' narratives. I use participant quotes, to enhance the transparency and persuasiveness of my interpretation (Riessman, 2003). I also consider my interpretation in relation to wider narratives and other literature around issues of illness disruption, identity and stigma. This representation is also reflexive of the co-constructed nature of the accounts (Mishler, 1986a).

1.7.1. The story tellers

The first of these chapters - Chapter Four - begins with an overview of the fourteen adults participating in this study, but more importantly introduces them as 'real people' who are living their everyday lives with epilepsy; the experts in the field of their own experience; and the story tellers who share that experience with us. These personal stories enlighten us as to the challenges faced by individuals with epilepsy, both in terms of coping with the everyday contingencies of life and in relation to changes in self-conceptions and personal relationships.

1.7.2. Agreement out of difference: a dominant plot across 'life with epilepsy' narratives

The dominant plot to emerge across the stories told is explored in Chapter Five. Here events are not defined in terms of their singularity but as the combined contribution they make towards a shared interpretation of 'life with epilepsy'. In the current study contributory events to the development of the dominant plot or story line for epilepsy included:

- *The process of discovery*
- *Searching for a cause*
- *Negotiating risk and uncertainty and,*
- *Striving for control*

Within this chapter my purpose is to explore the turning points and narrative elements of this dominant plot - as expressions of disruptive experience. This plot line comprises collective stories of diagnosis, seizure events and treatment, symptom management, risk

and loss of control, disclosure and stigma and stories of personal integrity. In focusing on what it is like to have epilepsy, I examine similarities and difference in narrative elements across my informants as well as in relation to other chronic illness narratives.

1.7.3. Living with epilepsy: stories of identity, biographical disruption and reconstruction

In Chapter Six the stories recounted provide us with a sense of how epilepsy impacts on daily living and how participants attribute meaning to those experiences. Emerging from all these tellings is a discourse of disruption; stories about a life disrupted by illness and a person's life-course being undermined – what Bury (1982) refers to as *biographical disruption*. While for some participants the disruption caused by epilepsy is seen to take its place amid other circumstances of daily living, for the majority the uncertainty of epilepsy, characterised by a loss of control, creates and perpetuates biographical disruption. My participants' stories portray identity changes which evolved over time as the discernible restrictions became an ever-present reminder of diminished independence, as well as identity transformations, as participants attempted to resituate themselves in the outside world.

1.7.4. Living with epilepsy: stories of undesired difference and stigma

Discrimination and prejudice towards people with epilepsy are still evident worldwide (GCAE, 2003; 2004; Snape et al, 2005). An appreciation of the attribution of stigma is important as stigma remains a major issue for people with epilepsy, and arguably a more pressing problem than the management of its clinical course. Thus, in Chapter Seven I explored findings in relation to the nature of 'difference' as experienced by participants in this study, and how that difference translated into stigma. Participants came to perceive the social meanings attached to having epilepsy and seizures as a threat to their status as normal and competent members of society and as a consequence strove be regarded as fully-fledged members, in relation to family, social and working roles. In this regard, the notion of stigma, as a powerful mediating framework for personal action and social involvement, was highlighted. A number of strategies developed and set in place by participants to avoid being exposed to enacted stigma emerge. The concept of self-stigma and its relevance for an individual's identity, as well as in relation to its potential impact on the identity of epilepsy as a unified, politicised group is highlighted. Targeted interventions to reduce epilepsy-related stigma are also discussed.

1.8. Reflections, summary of findings, implications and conclusions

In Chapter Eight I provide an overview of study findings together with implications for health and social care of people with epilepsy. Study limitations are discussed and future research opportunities are identified. Reflecting on the value of a narrative research approach I argue that epilepsy narratives can complement current approaches to epilepsy care as healthcare practitioners are able to become sensitive to the challenges, impacts and meanings of epilepsy, and as a consequence impact positively on traditional medical practice.

1.9. Locating myself

My way of seeing the world is shaped through many different lenses, including that of baccalaureate-level nurse with 20 years clinical experience; that of academic researcher; that of white, middle-class woman in her fifties; that of sister, divorcee, single parent to my daughter, grandparent, friend; and, not least that of my temperament and level of maturity. All these factors influence the tone and the content of my own story. Acknowledging their impact has helped me to further appreciate comparable influences on the narratives of my participants.

Before working in my current role as a Research Associate within an academic institution I had spent nearly two decades working as a nurse within the National Health Service. My clinical experience focused on acute surgical nursing and as an Operating Theatre Sister I had little professional exposure to individual's living and coping with chronic illness. Chronic illness presents different challenges to acute illness both for those living with chronicity and for those professionals who must meet the need for help and support. The manner in which I engaged in that process was at a personal level; deeply affected by the fact that both my parents were diagnosed with chronic conditions in later life from which they both died within six weeks of each other. The memories of attempting to care for them both, while struggling with the challenges of childcare and employment became the backdrop for my latent understanding of what chronic illness means.

Following my parents' deaths, my postgraduate studies provided an opportunity to enhance my understanding of medical and psycho-social models of living with illness, from which I was aware of the potential social and psychological impacts of living with a long-term condition. However, it was only as I began to work as a researcher on an epilepsy

stigma project that I became more aware of the many 'truths' and the depth of experience of those individuals who lived with the varying complexities of chronic illness over time, not least the potential impact upon a person's identity, both in relation to how they saw themselves and how they perceived themselves to be seen by others within society.

My interest in and experience of working on this initial research project led me to further research into epilepsy. I was struck by the range of perspectives held about this condition across both time and place and how despite medical advancements in the treatment of epilepsy there remained stigmatising beliefs (medical, political and social) which could lead a person with epilepsy to be seen in a lesser light or to have less rights in relation to those members of society perceived as being 'normal'. The more I read about epilepsy the more interested I became in trying to understand how these various constructions of epilepsy impacted upon the stories told by the individual with epilepsy and the meaning(s) those individuals attached to having the condition. This interest in epilepsy and its impact upon experience - through the elicitation of stories - allowed me to hear the voices of individuals and is one of the lenses through which I conducted this research.

This thesis represents one account of the experiences of living with epilepsy. It is important to note that participants self-selected into the study and as such the accounts may not reflect the generality, as those with a 'story to tell' and the ability to tell it are more likely to volunteer. Likewise, it is also necessary to acknowledge the influence of my own position in the construction of these stories, both in relation to how the data were collected and the subsequent interpretation of findings. Unlike my participants, I do not have epilepsy and at the start of this study, I had not experienced any serious health concerns and had not (rightly or wrongly) thought about the possibility of my own ill health. In considering my participants' position - while I no longer worked as a nurse, I used that experience and the experience of my own parents' ill health to enable me to reflect upon what story I might tell about the experience of change and potential disruption to a taken-for-granted life course.

Although professionally I was no longer employed by the National Health Service as a nurse I found it challenging on occasions to disengage myself experientially from this role. It was also a role that I had disclosed to potential participants as a strategy of 'mutual disclosure' (Holstein & Gubrium, 1995). What I learned from this was the constant need to keep a check on myself – I didn't feel as confident in the role of researcher as I did in the role of practitioner and it was important to keep reminding myself of why I was doing this project.

In addition, I carried the joint roles of being employed as an academic researcher by the same university at which I was also registered as a postgraduate student. The influence of one's professional identity upon the research process (Emerson & Frosch, 2004) and the potential difficulties of maintaining this balance (Lieblich, Tuval-Maschiach & Zilber.1998) have been articulated in the literature. I was aware during the interviews and the analysis of trying to balance my dual experiences. For example, I began my narrative encounters with participants confident in the fact that I had actively cultivated a rapport, enabling me to probe deep experiences. However, having developed this climate of mutual disclosure (Holstein & Gubrium, 1995), I found some of the interactions difficult to deal with. I was mindful not to allow myself to be viewed in a 'therapeutic' role; but also conscious that some participants positioned me as more than a researcher. Some participants focused on my previous clinical experience with the expectation that I might be able to bring about a positive change in their emotional wellbeing. Often I felt powerless within these interactions to bring about the difference they desired and at times powerless to seek out the 'deep and meaningful' for fear such probing might lead to emotional and / or physical upset for my participants. I used the support of my supervisors, researcher networks and my reflective diary to assist me to understand and reconcile the responsibilities and impact(s) of these various roles and to acknowledge how my role as a nurse and a previous representative of health services may have positioned me in a particular way in relation to some participants, thus impacting upon their narrative (Mishler, 1986a).

CHAPTER TWO

2. Narrative inquiry: linking philosophy and research method

2.1. Introduction

In this chapter I set out my epistemological and methodological positioning. The approach underpinning this study derives from my interest in the ideas of postmodernism, social constructionism, and narrative inquiry. I begin this discussion by outlining the origins of postmodernist thought and in doing so, highlight the relevance of this approach to facilitating understanding of the life experiences of those adults with epilepsy in my own study group (section 2.2.). Key tenets of social constructionism are then discussed (section 2.3.). This is followed by a critique of social constructionism in social science and medicine, which provides the backdrop from which I make my own position clear (section 2.4.). Next, I provide a justification for the value of narrative inquiry in providing an opportunity for people with epilepsy to have their own stories viewed not as secondary to the medical story but as stories that have their own primary importance. In a focused review of key literature around how individuals adjust to chronic illness I demonstrate how narrative can facilitate a more nuanced gaze into the everyday lives of those with a chronic condition such as epilepsy, as a means to understanding physical and psychosocial stresses, issues of stigma, the management of lifestyle choices and the nature of interpersonal relationships. Also how personal narratives can provide a means to understanding how individuals re-evaluate and reconstruct coping with the contingencies of everyday life and identity (section 2.5.). Finally, I outline the theoretical framework and research methods to conduct this exploration (section 2.6.).

2.2. Postmodernism

The term epistemology is the branch of philosophy that studies the nature of knowledge, in particular its foundations, scope, and validity; put simply how we come to know (Trochim, 2006). Epistemology poses the following questions: What kind of being is the human being? What is the nature of reality? What is the relationship between the inquirer and what is known? How do we know the world and what counts as knowledge? (Denzin &

Lincoln, 2000, p19). It is our beliefs in relation to the way we view these questions that subsequently shape the way we see the world and act in it.

As an intellectual movement postmodernism derives not from the social sciences but from art and architecture, literature and cultural studies. This development was paralleled in the field of medical studies by doubts about the possibility of biomedicine to explain and cure illness and relieve suffering (Hyden, 1997). For example, Gergen's (1973) paper, *Social Psychology as History*, was written at a time when social psychologists were becoming increasing concerned by the way their discipline favoured the values of dominant groups. The 'voice' of the man in the street was absent from their research practice which, because of its focus on decontextualised laboratory inquiry, ignored the real world contexts which give human action its meaning (Burr, 1995).

Proponents of postmodernism are interested in the relationship around language, meaning and power (see for example, Foucault 1972; Foucault and Gordon 1980) and thus, ultimately of representation. Reality is considered an outcome of an active process of meaning construction through social interactions (Gergen, 1994). The process of meaning construction is relational: events do not have meaning in isolation; rather, meaning is actively constructed out of chaotic experience via the use of language and other signals. Social processes and power inevitably play a role in this construction as they carry potential to influence the meaning-making process. Postmodernist beliefs in relation to knowledge construction therefore amount to an abandonment of positivistic approaches to research and to the Enlightenment ideals of an objective truth or grand narratives.

By way of further explanation, and as a means of asserting the relevance of a postmodernist perspective to aid understanding of the lived experiences of people with epilepsy, I focus attention on my own study group. Brenda, one of my participants made the comment: "*It's not just the actual seizures; it's living with epilepsy".* This comment not only reflects the sentiments of several others in my study group but, within the wider context, the anomalous position of people with epilepsy; for they find themselves members of what Frank (1991) terms a *"remission society"* (p.138) – those members of society who are effectively well but who cannot be considered cured; and who find themselves living in a world of the healthy, with the ensuing struggle to maintain wellness.

I argue that being diagnosed with epilepsy begins with the modern experience of illness (Frank, 1997) which is overtaken by medical and technical expertise and where suffering is

standardised (Miller & Crabtree, 2000), with the organisation of diagnostic investigations and potentially complex treatment regimes. The medical recognition of these experiences as symptoms, often expressed in language unfamiliar and potentially overwhelming to the patient, becomes the 'official' story. Here the normalising ideologies of the medical model - the search for control via rationality - and their related discourses, seek to restore order to the disruptions of illness (Becker 1997). However, conversely, they also serve to conceal the illness experience. For the individual with epilepsy no medical prognosis can predict seizure occurrence (Engel & Pedley, 2008); as a consequence those with epilepsy must manage an apparently healthy life in conditions of uncertainty.

Thus, living with epilepsy not only involves learning to deal with the physical impact of seizures, but also involves learning to cope with the associated, social and psychological consequences. It is the realisation that more is involved than the official medical story which constitutes the postmodern experience of illness; and from this perspective it must be acknowledged that other stories permeate the illness experience; those stories of suffering and meaning-making that inevitably accompany serious personal crises. It is my contention here then that the origin of knowledge and what is reality is 'socially constructed' and multi-vocal and that the story form provides a philosophical framework for understanding how individuals come to terms with the nature and conditions of their existence (Bruner 1986, 1990; Frank 1995; Kleinman 1988; Ricoeur 1984; Sarbin 1986). I subsequently argue that medical professionals should be encouraged to attend to patients' stories of living with epilepsy as ways of providing for their concerns and understanding their illnesses.

2.3. Social constructionism

Social constructionism has taken shape against the backdrop of 'postmodernism' (Burr, 1995) and requires a critical stance towards the taken-for-granted ways of understanding both ourselves and the world in which we live (Gergen, 1985). It challenges the view that conventional knowledge is based upon objective and unbiased observations of the world (Gergen, 1985). From a social constructionist perspective all knowledge is derived from viewing the world from one perspective or other and is in the service of one interest or other. As Cheek and Gough (2005) note it is important to emphasise that understanding 'reality' (and our knowledge of it), as socially constructed, is not an 'anti-realist' position, as some critics of postmodernism argue; what is at issue here is not belief in the real but confidence in its representation - in the words of Richard Rorty:

> *"to deny the power to 'describe' reality is not to deny reality"* (Rorty, 1979, p375);
>
> *"the world is out there, but descriptions of the world are not*" (Rorty, 1989, p5).

From this perspective knowledge is not a direct perception of reality. Rather, as a culture or society we construct our own representations of reality among us. In this way knowledge is not only contextual and time dependent, but also artefactual of history and culture. Furthermore, social constructionism holds at its core an understanding that knowledge cannot be separated from the socio-linguistic practices in which it is relationally achieved, being both shared and created in interaction. Thus, language is not a means of representing an external reality but only carries meaning in context; therefore all knowledge including psychological knowledge is historically and culturally specific (Gergen 1996; Nightingale & Cromby 1999). The beliefs constructed through the interactions between people in the course of social life may change with context, facilitating multiple perspectives and promoting greater subjectivity (Clifford, 1988; Atkinson, 1990).

The French historian and philosopher Michel Foucault provides insight into the concepts of postmodernism and social constructionism in the study of health and medicine (Buntin & Petersen, 1997). He attempted to show that the basic ideas which people normally take to be permanent truths about human nature and society change over time. Questioning the claims of modern human sciences (i.e. biological, psychological and social) that there are universal scientific truths about human nature, he argued that in fact they were often discourses about the ethical, political and historical commitments of a particular society (Foucault, 1972). In Chapter Three, I set out various constructions of epilepsy, where conflicting discourse is evident and can be tracked to time, place and context. As such these discourses constitute an active process of meaning construction through social interaction (Gergen 1994), which is changeable and evolving.

Foucault (1973a) posits that those who determine what knowledge is 'true' or 'right' also control the discourse; thus, from this perspective knowledge becomes power and power is knowledge. The prevailing discourses of subjectivity, bound up in this power, produce identities or roles. For instance, in his work *The Birth of the Clinic*, Foucault (1973a) locates the historical function of the clinic as a site of 'biopower'. Biopower analyses, regulates and controls, explains and defines the human subject, its body and behaviour (Burr, 1995). Here the body and its various parts are understood as constructed through discourses and

practice; in the case of medicine, through the clinical gaze of medical professionals exerted upon the docile body of patients.

Foucault's work around the issues of insanity (1965), criminality (1977) and sexuality (1985) offers a critique of the way in which individuals have been categorised and controlled, for instance, the development in psychiatry of categories of 'sane or insane'. Later elaborations have led to labels such as, for example, psychosis, neurosis, manic depression and schizophrenia. The development of criminology transformed crime into the study of 'criminals', categorising certain types of person as being predisposed to criminal behaviour. Turning attention once again to epilepsy, in Chapter Three I draw on Foucault's work to position the various discourses surrounding epilepsy as a means to explain how understandings of epilepsy have been conventionally cast, and how cultural and social forces across time and place have contributed to the categorisation and control of those with the condition – epilepsy as demonic possession, epilepsy as contagion, epilepsy as neurosis or insanity, epilepsy as stigma; and how epilepsy has come to be seen as a particular type of biomedical object.

Following Foucault, the 'prevailing discourse' about phenomena such as illness has the potential to exclude those who appear 'different'. A sense of knowledge, mastery or expertise develops around such discourses, particularly those presented by the powerful or elite (in this case the medical establishment). This disciplinary power provides the guidelines for how patients should understand, regulate and experience their bodies and is actioned via practices such as observation, examination, measurement and the comparison against an established set of norms – components of contemporary medicine's 'evidenced-based practice' regime.

However, in the field of epilepsy, the dominance of the medical discourse is not without uncertainty as scientific knowledge and medical understanding about the condition is still evolving. Even today uncertainty and confusion in relation to what constitutes a definition and diagnosis of epilepsy remains evident (Reynolds & Rodin, 2009). By way of example, differences in the definition of epilepsy (see Figure 1) beg the question: what is the potential clinical and psychosocial impact of this uncertainty and confusion for those people living with condition?

I would suggest that these fundamental differences in the medical conceptualisation of epilepsy - dependent on the consulting physicians' 'school of thought' – likely translate into

differences in approach to epilepsy management, both in terms of clinical treatment and in relation to consideration of an individual patient's holistic care needs. The lack of medical consensus in relation to epilepsy etiology and treatment regimens is illuminated in many stories told by participants in my study, and as such challenges the 'grand narrative' of modernity (Lyotard, 1984), wherein medical and scientific uncertainty itself shatters certitude, since any knowledge heralded as 'sure' may be invalidated.

The journal *Epilepsia* recently conducted an on-line public survey asking directed questions related to the 2014 Operational Definition of Epilepsy (ILAE, 2014). Interestingly the reported results (Mathern et al., 2014) demonstrate clear disagreement. Three key questions addressed: (1) criteria for when a person could be considered to have epilepsy after a single seizure; (2) whether individuals with reflex seizures (unprovoked) have epilepsy; and (3) when epilepsy could be considered "*resolved*."

Figure 1: Medical definitions of epilepsy

Definition 1 (Engel & Pedley, 2008)	**Definition 2** (Fisher et al., 2005)	**Revised Definition 2** (Fisher et al., 2014)
A group of neurological conditions, the fundamental characteristic of which are recurrent usually unprovoked seizures. A common operational definition is two or more unprovoked seizures occurring more than 24 hours apart.	A disorder of the brain characterised by an enduring predisposition to generate epileptic seizures and by the neurologic, cognitive, psychological and social consequences of this condition. The definition requires the occurrence of at least one seizure.	A person is considered to have epilepsy if they meet any of the following conditions: • At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart. • One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years. • Diagnosis of an epilepsy syndrome ○ Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.

Of the 476 responders that started the survey, 324 (68%) completed it; of whom 43% agreed with the ILAE report recommendation that if the risk of a second seizure after a first one was 61–90%, then a person could be considered to have epilepsy. More medical professionals agreed with the 61–90% risk criterion (55%) compared with patients (21%), while more patients indicated that epilepsy should only be defined after two unprovoked seizures (51%) compared with medical professionals (21%; $p < 0.0001$). The majority indicated that reflex seizures qualify a person as having epilepsy (79%). As recommended in the ILAE report, 51% agreed that the definition of a person with "resolved" epilepsy would be 10 years seizure-free and off medication for the last 5 years. More medical professionals agreed with this definition (59%) than did patients (37%), while more patients indicated that epilepsy is never resolved (32%) than did medical professionals (7%; $p < 0.0001$). These findings highlight controversy over the new 2014 Operational Definition of Epilepsy and differences in perspective between medical professionals and patients' opinions.

However, the dominance of the medical discourse often means that other types of knowledge and / or opinion are considered less justifiable and not equal as they derive from those thought less qualified to speak – for example, patients (Frank, 1997). Similarly, Andermann (2000) notes, in her description of how epilepsy is viewed according to biomedicine and the scientific literature, that the narrative of medical researchers is often seen to dominate the narratives of those with epilepsy; and concludes that the subjective experience of people dealing with illness is often overlooked by focusing solely on this approach.

2.4. Critique of social constructionism in social science and medicine and my own positioning

Despite an ever growing literature on social constructionism within medical sociology, its application to the study of health and illness is debated. For example, Bury (1986) and Nicolson and McLaughlin (1987) present opposing views about its usefulness and legitimacy in aiding understanding. While Bury notes that interest in social constructionism has provided a useful avenue for the introduction of fresh ideas into medical knowledge, his critique leaves little doubt that he views its usefulness as limited. The weakness of social constructionism, according to Bury, centres around five main criticisms, namely; the difficulty of incoherence, the difficulty of realism, the difficulty of reflexivity, the difficulty of relativism, and, the difficulty of the sincerity and humanity of medical practitioners - all of which Nicolson and McLaughlin argue can be answered and therefore do not invalidate the

strength of social constructionism. In making my own position clear, firstly, I do not necessarily question the reality of the biology and physiology but rather focus on the mode in which the chronic condition is known, experienced and interpreted by an individual both independently and socially. Neither do I dispute that biomedical discourse prevails in health care language and has influenced health care policies and practices for many years.

A further criticism levied against social constructionist and postmodern perspectives is that they fail to address the 'embodied' character of contemporary human endeavour, for example, the way patients experience self and body during illness (Sampson, 1996; Crossley, 2000a, 2000b;). For example, Sampson argues that whilst social constructionism engages in discourses about the body and how it is constructed in history and culture, it fails to consider *embodied* discourse. Similarly, I have drawn on Foucault's (1982) work to aid understanding about how people with epilepsy within our society might be "*made subjects*" (p208) in biomedical terms (for example, the treatment of seizures) and how we can use this perspective in helping us to see the conditions which need to be put in place in order for epilepsy to be looked at in a particular way. However, such diagnostic labelling positions the subject as constituted entirely through discourse rather than having a pre-discursive existence. I argue, then, that whilst postmodern ideas about multiplicities and the relative nature of 'truth' promote awareness about prevailing discourses and ideas, they can neglect consideration of individual agency or meaning and fail to take account of how the condition is experienced; a point to which I shall return to in section 2.5. By fixing the focus solely on medical surveillance and domination, we fail to consider how individuals respond to the clinical gaze. It is therefore important to consider both the dependency and the resistance demonstrated by patients in relation to medical expertise and to social contexts, and to acknowledge the 'lived experience' of the body. In the words of Shilling:

> *"…it is necessary to allow for lived experience, for the phenomenology of the body. Bodies may be surrounded by and perceived through discourses, but they are irreducible to discourse. The body needs to be grasped as an actual material phenomenon which is both affected by and affects knowledge and society"* (Shilling, (1991, p664).

Lastly, by assuming a reflexive position I acknowledge the possible status of social constructionism as yet another discourse which may offer no greater claims to knowledge than those it criticises. Whilst accepting the distinction between discursive descriptions and the world itself my primary purpose in eliciting stories was to pay special attention to the way in which individuals living with epilepsy described their experiences. For example:

- How did they come to interpret what having epilepsy meant?
- How did they see themselves as a consequence of this interpretation?; and,
- What impact did this interpretation have on the way they interacted with others?

Answers to these questions are revealed within my analysis.

2.5. Narrative inquiry

In the following section I present my rationale for a narrative-based research approach which concerns itself with the way in which individuals tell stories, impute meaning to experience, and how such meaning is subsequently transmitted and interpreted - life and narrative being inextricably linked.

Narration and storytelling, whether about oneself or others, are not new notions but they are universal ones (Bury, 2001). Since the dawn of language, narration has been a dominant form of human communication (Poindexter, 2002). Stories are an intrinsic part of one's society and culture; influencing all aspects of our lives and defining our values, aspirations and prejudices. Listening to stories to reach understanding is also not new (Poindexter, 2002). Story telling derives from ancient history; the origins of which are rooted in non-Western societies, traditionally handed down from generation to generation. Anthropologists have documented folk tales and oral histories by spending time with tribal chiefs to understand inner life and theologians have examined ancient stories to find messages and lessons (Poindexter, 2002). Originally storytelling is believed to have been used to calm the fears or concerns of a family or a clan. People found stories interesting and informative and began to listen. A good 'storyteller' recounting heroic or other important events was always respected and often reached a position of power. In the history of storytelling, figure heads such as priests, judges and those that ruled were perhaps the earliest to use the medium of narration effectively (SparkNotes Editors, 2004).

The oldest surviving tale in the history of storytelling is said to be the epic, *Gilgamesh* (SparkNotes Editors, 2004); originating from Ancient Sumeria. It was originally written on 12 clay tablets in cunieform script. The story recounts the deeds of a famous Sumerian king (somewhere between 2750 and 2500 BC). We know also, through ancient Egyptian records, that the sons of Cheops entertained their father with stories. These writings, believed to be from the period 2000- 1300 BC show that one son told a tale of magic, another told of deeds of the forefathers and a third told a contemporary tale (Lockett,

2007). This provides evidence not only that the art of storytelling existed but that it was used for entertainment, communication and religious purposes; and reflected the knowledge and wisdom of early people, which tied them to a common culture and beliefs.

Storytelling is also evident in African history through the tellings of Aesop, a slave. He recounted stories and fables handed down through generations as well as tales of his own that have lived until modern times. Although Aesop was reported to have lived about 550BC, his stories were not written down until 300-250BC (Lockett, 2007). The same pattern can be observed in China and India, where ancient fables only appeared in written form many years after they were originally told.

As in other parts of the world, storytelling also held a prominent position in American history with stories of heroics, sacrifice and floods (Lockett, 2007). In attempting to convert the natives of Central and South America to Christianity, documents and stories that recorded events were burned by priests. However, North American storytelling lived on through oral stories told at pow-wows and around camp fires. Even today the storyteller holds an important place in the culture of Native Americans (Lockett, 2007).

Storytelling conserves the oral language from previous cultures, while introducing it to the language of the present generation. It is believed by most historians and psychologists that storytelling is one of the many things that define and bind our humanity (Lockett, 2007). Thus universal, cultural and individual levels of human existence are tied together with narrative threads (Bury, 2001). In recent times the study of narratives has received considerable renewed interest in both social sciences (Bury, 2001) and medicine (Greenhalgh & Hurwitz, 1998; 1999) Illness narratives, I would argue, are particularly appropriate when existential crises and disruptive events threaten an individual's sense of normality and narrative coherence. In this chapter I discuss the relationship between the present study and other studies of patients' narrative accounts of illness and contend that illness narratives are a suitable tool for exploring the individual and the socio-cultural implications of having epilepsy.

Narrative inquiry has the potential to formulate and express a central aspect of being ill in modern society (Frank, 1995), namely the difficulty of giving voice to suffering and to the life-world context of illness (Hyden 1997). Interest in narrative has risen with the emergence of postmodernism and, as outlined earlier in this chapter, its scepticism towards the 'meta-narratives' underpinning scientific theory and knowledge (Lyotard, 1984). Illness

narratives offer a research paradigm that involves the collection and interpretation of stories – the central tenet being attention to the potential of stories to give meaning to events and experiences in people's lives (Mishler, 1986a; Bruner, 1990; Kleinman, 1999). Some of this literature focuses on lived experience of a specific illness, for example Bury's (1988) study of adults with rheumatoid arthritis, while others discuss a range of conditions and their potential impact for narrative identity (for example, Kleinman 1988; Becker 1999).

Mishler (1986a) conceptualises narrative as one of many modes of transforming knowing into telling. Human beings are "*immersed in narrative",* telling stories in a "*virtually uninterrupted monologue"* and tirelessly listening to and recognising in their own stories the stories of others (Polkinghorne, 1988, p160). Telling stories is the means by which individuals come to know, understand, and make sense of the world, which Mishler (1986b) argues applies equally to interview respondents who, when given the opportunity, often present their experiences in story form. A review of narrative literature also suggests an inextricable link between narrative and identity. Through telling their stories individuals can express their identity, relationships and emotions, orientate and organise life events, in some instances gaining a sense of perspective upon these events, and can often solve problems (see for example, Connelly & Clandinin, 1986, 1990, 1994; Ricoeur 1988; Bruner 1990, 1991; Riessman, 1990, 1991, 1993; Somers, 1994; McLeod, 2000). In the words of Andrews:

> *"Stories are not only the way in which we come to ascribe significance to experiences, they are one of the primary means through which we constitute our very selves…we become who we are through telling stories about our lives and living the stories we tell" (*Andrews, 2000, p77-78*).*

Within the context of the current study the illness narrative approach provides a vehicle for examining how medical, social, and moral discourses, social interaction and power combine to affect the meaning and lived experience of epilepsy. As such, narrative inquiry provides a method which I would argue is more respectful and representative of my research participants.

Kleinman (1988) argues that the real meaning of the illness narrative is what the physician and the individual who is ill must explore if healing is to be sought. As an advocate of the narrative approach he further argues that illness narratives are important both within and beyond clinical practice settings. Within clinical practice, patients with chronic illness need to have a 'witness to suffering' and to their existential fears. Attention to illness narratives

also assists in the practical management of such illness. It is for these reasons that patients will turn to medical professionals, even when they know medical treatment may be limited (Gabe et al., 2004). Outside of the clinical arena, illness narratives help deal with the altered situation and potential disruption occasioned by the onset of illness. Kleinman (1988) asserts that illness narratives assist in addressing and responding to the existential questions of *"Why me"?* and *"Why now"?*, and to the *"What can be done"?* question of order and control (p29). He goes on to suggest that these are questions which the medical model finds difficult to answer, especially in chronic illness where etiology is sometimes unknown and where the condition may be difficult to treat; a situation of considerable concern for people with epilepsy.

Previous research on how individuals adjust to chronic illness highlights a noticeable thread, the need to distinguish disease phenomena as seen from the practitioner's perspective, - from illness, as a phenomenon seen from the perspective of the sufferer. The latter perspective, by prioritising an 'insiders' view, focuses directly on the subjective meaning of experience within the context of everyday life (see for example: Schneider & Conrad, 1983; Williams, 1984; Kleinman, 1988; Charmaz, 1990; Kleinman et al., 1995; Frank, 1997; Becker, 1999). The strength of narrative lies in its ability to foreground the human drama surrounding illness, a point expressed by Sacks (1987), himself a neurologist, speaking critically of authorised medical discourse:

> *"…[*medical histories*] are a form of natural history – but tell us nothing about the individual and his history; they convey nothing of the person, and the experience of the person, as he faces, and struggles to survive his disease. There is no 'subject' in a narrow case history; modern case histories allude to the subject in a cursory phrase* ('a trisomic albino female of 21') *which could as well apply to a rat as a human being" (*Sacks, 1987,pviii*).*

Sacks further argues that narrative discourse serves as a vehicle for bringing persons, with their particular experiences of illness, into focus:

> *"To restore the human subject at the centre – the suffering, afflicted, fighting human subject – we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relation to disease – in relation to the physical"* (Sacks, 1987,pviii).

Narrative has not only been identified as a mechanism for illuminating chronic illness issues but also as a vehicle for enabling individuals to re-evaluate and reconstruct coping with contingencies of everyday life and sense of self (Bury, 1982; Kleinman 1988; Garro, 1994;

Becker, 1999). However, with few notable exceptions, (Good & Good, 1994; Faircloth, 1998, 1999; Nijhof, 1998), the narratives of people with epilepsy have been overlooked. Consequently, I argue, that the potential for healthcare professionals and others to learn from their unique stories and experiences has also been overlooked (Snape; in Fernandes et al., 2011).

In the discussion that follows I summarise relevant literature that reflects concepts on disruption, sense of self and identity, stigma, and narrative. Such concepts are potentially important to the experience and interpretation of living with epilepsy and so they serve to orientate the reader to my research project. In the analytic chapters that follow, my interpretation will refer back to this literature as a means of making sense of my participants' stories and determining whether and how my findings, confirm, challenge or extend the work of earlier researchers.

2.5.1. The experience of chronic illness, disruption and narrative

> *"Chronic illness* [is] *a state or passage of care for long-term pain and suffering that may not be cured"*. (Martin & Peterson, 2009, p579).

The social meaning and lived experiences of those with chronic illness such as epilepsy take shape via body, self and identity relationships; what Merleau-Ponty (1962) refers to as ways of *being-in-the-world.* There are both objective and subjective elements to being-in-the-world. The objective body is represented in medical discourse. The subjective body includes the physical body; how the individual, through the body, acts in the world (Csordas, 1994); and how individual action, perception and identity are shaped by such action. The subjective body in the social construction of illness provides a set of meanings and explanations often not accounted for within the linear biomedical model used by many health professionals to interpret the illness experience.

Parsons (1991) demonstrated decades ago how illness disrupts a person's responsibilities and capacities. The sick person is released from social obligation during illness but in return must appropriate an identity as sick. Parson's 'sick role' carries the expectation that ill people try to get well, cease to be patients and return to their normal obligations. In the 'remission society' (Frank, 1991) - among which I include people with epilepsy – people return, but obligations are never again what used to be 'normal'.

Chronic illness challenges this view that life is an orderly process (Becker, 1999) by disrupting the taken-for-grantedness of the life course. Life is no longer predictable, illness directly affecting the capacity of the person to function and act in particular ways (Strauss, et al., 1984). A number of social scientists have undertaken research which examines the disruptive and debilitating effect of chronic illness on individual identity (see for example: Bury, 1982; Strauss, et al., 1984; Conrad, 1987; Corbin & Strauss, 1987a; Kleinman, 1988; Becker, 1999). When chronic illness occurs it poses questions about how one might ride such disruption. Taken-for-granted assumptions about one's routines and identity become fractured and individuals face the daunting task of re-integrating somatic and biographical disruption into their self-image in order that a sense of self can be restored.

Bury (1982) conceptualised chronic illness as constituting a major disruptive experience which he terms 'biographical disruption'. He intended to show that chronic illness causes a break in people's lives, acting as what Giddens (1979) has called 'a critical situation':

> *"We can learn a great deal about day-to-day situations in routine settings from analyzing circumstances in which those settings are radically disturbed"* (Giddens, 1979, p123).

In defending this idea Bury (1982) identified three facets of disruption which he linked to the unfolding of a chronic illness. First, there is the "*disruption of taken-for-granted assumptions and behaviours; the breaching of common sense boundaries"*. Second, and more profound, are the *"disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved"* (p.169). It is here, as discussed below, that concepts of 'narrative reconstruction' and the symbolic attempt to repair ruptures between body, self and society have the potential to provide insight into meaning and experience of chronic illness (Williams, 1984; Hyden, 1997). Third, there is the *"response to disruption involving the mobilisation of resources, in facing an altered situation"* (p170). Bury (1982) also highlighted how the onset of chronic illness not only disrupts structures of meaning but also relationships. For example, illness can lead to dependency on others, which has the potential to violate societal norms of reciprocity and mutual dependency. Thus, the degree of support afforded by family, friends and work colleagues, and the ill person's ability to mobilise such support, become crucial to the way in which illness is subsequently experienced.

An appreciation of such disruption involves the wider recognition of suffering and the social context in which it is experienced. Metaphorically, it can be aligned to *"a tear in the fabric*

of ones life" (Radley, 1994, p145), raising uncertainty about the assumptions upon which that life was based. As Scambler (1989) indicates, in his study of epilepsy, symptoms may appear frighteningly 'out of the blue', leaving the individual not only facing a changed situation, but also the potentially stigmatising reactions of others.

The subjective meaning of chronic illness within the context of biographical disruption has, according to Bury (1988), two distinguishing facets. First, there is the meaning of chronic illness that can be viewed in terms of its practical *consequences*, for example the management of symptoms, the intrusion on family and social life; and second, the meaning of illness when viewed in terms of its *significance*. By this Bury (1988) means that different conditions carry different degrees of symbolic imagery. The relevance of the latter for people with epilepsy lies in the connotations individuals attach to their condition; for example the cultural meaning of epilepsy may lead to reports of feeling different, feeling stigmatised and experiencing loss of control across a number of life domains.

This concept of a threatened biography has also been explored by Corbin and Strauss, (1987a). They identify three dimensions namely; biographical time, conception of self and bodily capacity. They argue that because we engage with the world and others through the medium of our bodies, when bodies become affected, the consequences are experienced at two different levels. The first, at the level of *performance,* carries implications for what and how an individual must do things. For the participants in my study this also involves having the stamina to continually redefine what they want. The second consequence is in relation to *identity* and how the illness will reflect upon the individual as a social being. Evidenced in some of this work (Bury, 1982; Kleinman, 1988) and in the work of others (Williams, 1984; Garro, 1994; Becker, 1999) is the use of personal narrative as a means of conveying the disruption of illness, especially chronic illness.

The concept of a threatened biography and resulting uncertainty surrounding chronic illness brings to the fore an argument presented by Charmaz (1980) that self-conception is the prerequisite of illness management and its changes may seriously affect an individual's ability to cope, and undertake important social roles. She goes so far as to speak of a *'loss of self born out of daily life'* (Charmaz, 1983, p169-170), especially with regard to chronic illness - which may effectively undermine the normalisation strategies adopted by individuals, and as such, fundamentally change their life and life-style. Charmaz (1983) points out that a loss of self in one area often leads to a loss within another. The greater

the loss of control and the amount of potential embarrassment from the unpredictable illness, the more likely the individual's self-concept suffers and he or she will restrict his or her life voluntarily (Goffman, 1963). The concept of loss of self may be particularly relevant to people with epilepsy in that, as I will show, they are continually redefining self in response to not one but several 'critical incidents' in the form of recurrent seizures. Charmaz (1983), in highlighting the broader significance of chronic illness suffering, presents a perspective not dissimilar to that of Bury's (1982). It is in a paper by Williams (1984) however, that we are introduced to the idea of 'narrative reconstruction' which serves as an addendum to the story of disruption.

According to Williams (1984) the way in which we maintain a sense of life-course is through narrative. It is here that stories weave together varying events and experiences that constitute a life. When life is disrupted meaning is sought through *narrative reconstruction*; an attempt to link up and reinterpret events in the light of an individual's changing relationship to the world in which they live. Through the occurrence of narrative reconstruction disruption and suffering can be brought under some form of meaningful control and a legitimate place for their condition found within their lives. It is in this respect that Kleinman (1888) suggests it is possible to see that narratives are more than a reporting of illness – whether it be to medical practitioners or others; they are efforts to integrate or re-integrate individuals into their social worlds.

Williams (1984) suggests that his participants' attachment to significant events added a moral, and sometimes openly 'political' component to their accounts. Throughout Williams' case presentations we become sensitised to ways in which narrative reconstruction can be used to, *"reconstitute and repair ruptures between body, self, and world by linking and interpreting different aspects of biography in order to realign present and past, self and society"* (p197). This process of repair is what Bury (1991) later refers to as reconstruction work or *"legitimisation"* and may be accomplished through *"establish*[ing] *an acceptable and legitimate place for the condition within the person's life"*. This key concept is also embedded in narrative accounts of persons who suffered disrupted lives as a consequence of temporomandibular joint (TMJ) pain and dysfunction (Garro, 1994). Through their narratives about TJM, participants sought to change the way the condition was responded to and understood, and aspired to increase both medical and public awareness of TJM as a means of *legitimising* their suffering. By viewing respondents' stories at a conceptual level that takes in the individual, social and political characteristics

of narrative formations, Garro (1994) demonstrates how these narratives not only help people make sense of what is happening by providing *'an arena for negotiation of reality'* (Early, 1982, p1491), but also facilitate the notion of narrative research as forms of politics. By broadcasting 'voices' that are excluded from or neglected within dominant political structures and processes (Squire, 2007) this study aptly demonstrates how narratives carry implications for both healthcare intervention and policy making. In this way illness narratives not only assess the protagonists' personal meanings but incorporate and build upon cultural ideas about the causes of illness and illness itself - something which also makes the illness part of the shared culture (Hyden, 1997).

A study conducted by Carricaburu and Pierrets (1995) raises important issues about elements of *biographical reinforcement* as well as disruption. The analysis centred on managing HIV infection in everyday life. While all interviewees had been deeply disturbed by their HIV infection and its effects on their health, their reactions to a positive immune status differed considerably. So, for example, for homosexual men, HIV-positive status served to *reaffirm* their struggle - personally and politically. Prior to infection, gay men had viewed their homosexual identity in a positive light; HIV-positive status posed an assault to this identity and had to be incorporated into their sense of self and pasts. For gay men *"this disruption set off a complex process wherein the components of their identity related to homosexuality assumed special importance"* (p83). All men spoke positively with regard to being gay. They also *"placed their own biography within the history of the generation of men who fought for the recognition of homosexuality and the right to be different"* (p83).

In contrast to homosexual men, the passage to HIV-positive status for haemophilic men served only to *confirm* a life-time's illness experience and as such was a *reinforcement* of their biographies. There were however exceptions to this; in the cases where haemophiliac men had denied their haemophilia or *"down played"* their condition, HIV infection did cause disruption. As a result of this disruption these men had to rethink their pasts and assimilate not only their haemophilia but also their HIV-positive status into their biographies. This aspect of the research has resonance with the notion of 'restored self' (Charmaz, 1987) and with the stages of identity articulated by Corbin and Strauss (1987b) namely; defining and redefining self, refocusing of direction, and integration.

A further point I draw from this work, which bears relevance to my own study, is that AIDS like epilepsy carries the fear of stigma and affects the collective identities of people who

suffer from the condition. So, as Carricaburu and Pierrets (1995) argue, being HIV-positive (likewise, having epilepsy) is not just a matter of being individually *infected*, (impact on one's personal identity) it is also a question of being *affected* as part of a group (impact on one's social identity) which has its own history of collective impact.

Collectively these works illustrate the importance of investigating the effects of illness or disruption in a social context. Personal narrative is a means by which the links between body, self and society are articulated (Williams, 1984; Bury, 2001) and provides a *"primary means of accessing the world of bodily experience which is essential to our understanding of that experience"* (Becker, 1999, p26). Theoretically, it can be argued that epilepsy not only represents a 'critical event' (Giddens, 1979) but as a consequence of continuing seizures represents multiple critical events that disrupt individuals' lives. Personal efforts to create continuity in a life so disrupted can be summarised as the attempt to reconstruct life history (Williams, 1984), or seek *legitimisation* (Bury, 1991). Yet, despite the relative success of advances in anti-epileptic drug and surgical treatment options, the uncertain, chronic, and stigmatising nature of epilepsy may make it particularly difficult to integrate into one's biography. Conversely, as Pound and colleagues note:

> *"Bury's theory of biographical disruption may not be applicable to those who have prior experiences of illness, or indeed those who have had any experiences which have led them to question the foundations and trajectories of their lives". (*Pound et al., 1998, *p491).*

In either circumstance, surprisingly little analytic attention has been afforded to personal narratives of people with epilepsy where "*biographical reflection"* or "*biographical reconstruction"* (Carricaburu & Pierret, 1995) is likely to occur against a backdrop of potentially disruptive events and experiences.

2.5.2. Chronic illness stigma, identity and sense of self

Many chronic illnesses carry a stigma. The embodied models of society shape understanding about how a healthy, normal, whole person appears, acts, feels, and thinks. Thus an attribute that causes the person to deviate from what is perceived to be normal is a stigma (Goffman, 1963). This attribute is perceived as violating the expectations of normal behaviour or appearance; it is "*an attribute that is deeply discrediting"* (p3) and negative. Stigmatised persons are treated and perceived as non-persons. As a consequence their identities are *"spoiled"*. Deviant people are viewed as somehow responsible for their abnormality and as such their moral character is also brought into question. Paradoxically,

those who are stigmatised share societal views relating to what is normal, often recognising and acknowledging they fail to match the model.

In Chapter Three I outline the empirical support for epilepsy as representing both a socially and culturally stigmatised condition. I shall not rehearse these arguments here other than to note that, since ancient times epilepsy was thought of as both a sacred disease (by the ancient Greeks) and as a demonic disease (in the New Testament); in modern times it is still associated with discrimination and biased attitudes derived from ignorance, helplessness, and fear; and, for many people with epilepsy, dealing with the stigmatising impact of the illness is worse than dealing with the disease itself.

Arnston and Drodge (1987) observed, in stories told by epilepsy patients in a support group that the name of a disease often served as a label of stigma. These participants' stories revealed that the term 'epilepsy' brings with its medical definition a collection of legal restrictions and social reactions that can affect a sense of loss of personal control over the lives of people with epilepsy. This finding resonates with Goffman's (1963) claim that members of stigmatised groups perceive themselves as possessing less agency than the so-called 'normals'.

It is not surprising that changes in health brought about by feared and stigmatised conditions such as epilepsy can lead to changes in identity. Not only can epilepsy spoil a person's pre-diagnosis identity - causing them to feel they are less than a whole person – but the message of 'stigmatised person' is confirmed throughout the post-diagnostic experience because stigma is communicated in interactions with others. Stigma and shame were central to interpreting the meaning of epilepsy in a study conducted by Scambler and Hopkins (1986). Here, the authors reframed the idea of stigma as pertinent to life with epilepsy:

> *"Enacted stigma refers to instances of discrimination against people with epilepsy on the grounds of their perceived uncertainty or inferiority […] Felt stigma refers principally to the fear of enacted stigma, but also encompasses a feeling of shame associated with being epileptic".* (Scambler & Hopkins, 1986, p33).

Thus, the stigma of epilepsy appears wrapped up in interpersonal communication within mixed contexts and in interactions with various others, creating a source of tension between the person's private self and public social identity.

Charmaz (1980) describes the ways in which the stigma associated with chronic illness may lead not only to an experience of low self-esteem, but also to withdrawal by placing restrictions on one's social activities and quitting work. The spiralling effect of living a more restricted life leads to a potentially increased sense of loss. The individual's ability to give or to contribute in an equitable way may be compromised and, as such, an opportunity for self-validation through meaningful interactions with others is lost. Experiences of being discredited, devalued, embarrassed or ignored also contribute to the growing isolation of ill individuals and to their subsequent reappraisals of self – a finding relevant to people with epilepsy, noted previously by Schneider and Conrad (1981).

The study discussed earlier conducted by Carricaburu and Pierrets (1995), aptly demonstrates how narrative provides a vehicle for drawing attention to the interrelations between the individual's experience, his life story and the history of his reference group, and provides a powerful means for communicating and giving meaning to that experience. In this regard an analysis of epilepsy narratives *may* provide further differentiation of existing, pre-set, encompassing concepts such as stigma and in so doing highlight the potential differences in the experience of an altered identity.

For Sclater (2003) the attraction of studying narrative lies in its ability to facilitate thinking about a human subject who is socially situated and culturally determined, while at the same time expressing a unique individuality. A narrative study conducted by Nijhof (1998) lends support to the view that when people with epilepsy were allowed to 'speak freely' differences in the interpretations of the self could be discerned. This heterogeneity appeared not only to be a matter of differentiation but also a matter of opposition. Interpretations in terms of abnormality and disease were often counteracted by interpretations of normality in the same life story. For example, medical interpretations of epilepsy appeared to be restricted to the stories relating to the early phase of the condition. Later, participants appeared to have freed themselves from a medical denomination; giving up the social advantages of a medically legitimised role. However, in place of the successfully contested label of disease, they were faced with other disconcerting labels, especially that of abnormality. Most participants, in their normalising, appeared to defend themselves against abnormalising 'others' and in this way their stories could be read as successful resistance to medical interpretations. Yet these stories can also be read as an indication of a less successful opposition to the abnormal interpretation of 'others'. Having introduced the language of normality as an alternative, participants

appeared to struggle with this labelling. This struggle, according to Nijhof (1998), would appear a difficult struggle because the labelling did not appear to be explicitly stigmatising. The abnormality attributed to individuals with epilepsy by 'others' was vaguely defined, poorly articulated and ambiguous. Thus epilepsy appeared not to have a homogeneous meaning but was constructed as a heterogeneous social phenomenon.

Similarly, Faircloth (1998) draws on narrative analysis to explore subjective meanings of the nature of the epilepsy experience, in which he concerned himself with concepts of identity and difference. The approach is underpinned by the assumption that selves and stories are linked; its focus therefore is on the relationship between language, experience and identity. In his analysis of participants' stories he is able to show the moves and changing meanings of epilepsy from individual to individual. Faircloth (1998), by demonstrating such difference notes the lack of commonality between individuals grouped under the umbrella of epilepsy and concludes there is not a universally shared origin of an epilepsy 'identity'.

Identity creation through story telling has also been explored by Charmaz (1987), who proposed four common stages of identity potentially communicated in illness narratives. These stages include; the supernormal identity, the restored self, the contingent personal identity, and the salvaged self. In the supernormal identity stage, patients feel a determination to maintain their old stories. They become less optimistic in the restored self stage, but still resist fully accepting the changes brought about by their condition. An admission of new limitations and the prospect of a changing identity occurs in the contingent personal identity stage; while the salvaged self sees the emergence of a new identity that integrates aspects of the pre-illness identity with aspects of the new self. These types of illness narratives and identity stages illustrate ways in which patients might cope with illness. For instance, Frank (1991), recounting his personal experience of a heart attack and cancer, claimed that the way in which he lived in his body changed significantly from his former life. Unfortunately, he also noted the failure of his physicians to recognise and address his psychosocial needs, leaving him to deal in isolation with his fear and to make sense of his life plans and his altered sense of self.

Frank (1997) suggests that the stories of the chronically ill reflect the fearfulness surrounding illness; fear that is associated with the individuals' inability to predict a positive future based on a sense of agency. He offers the following explanation:

> *"The conventional expectation of any narrative, held alike by listeners and storytellers, is for a past that leads into a present that sets in place a foreseeable future. The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable"* (Frank, 1997, p55).

It is in this regard that Frank (1991) suggests much can be learned by re-framing illness less as a catastrophe and more as an opportunity to create a new story and in so doing, a new identity. Because reasserting one's story after a diagnosis of epilepsy may prove difficult, individuals can look to another option; they can create a new story. Good and Good (1994) note that in the biographical accounts of people with epilepsy in their study group, participants telling the stories were in the midst of their story. Analysis revealed that endings were often hypothetical, with feared outcomes often juxtaposed against those hoped for. By examining the structure of these biographical accounts, Good and Good (1994) provide an important means of investigating how culture influences the experience of illness and the efforts undertaken by suffers to rebuild life-worlds fractured by illness. The researchers demonstrate how participants were still engaged in a quest for cure, imagining alternative outcomes, evaluating the potential meaning of the past and seeking treatments. This process can be likened to what Schafer (1981) terms 'self-stories'. 'Self-stories' are functional. They are coping stories; the purpose of which is to create meaning and to reaffirm the presence of the self. The assumption is that via reflection we can consider a variety of perspectives, including temporal and spatial contexts, and through the telling of these stories of experiences, we become mindful of their significance. This is what Frank (1995) argues as the ethical dimension of the narrative construction of identity:

> *"The moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one's story is shaping into, entailing the requirement to change that self-story if the wrong self is being shaped"* (Frank, 1995, p158).

Thus, whilst other stories are always possible, life is lived in relation to decisions; each decision establishing a different way of telling the story and a different way of being.

Illness narratives in this sense provide a means by which patients can reaffirm and recreate themselves while coping with the fear that accompanies their changed health status. I suggest that a consideration of a phenomenology of everyday life, activities and subjectivities (identities) enables penetration of the dominant clinical gaze on epilepsy by viewing the experience of those with epilepsy through alternative frames of reference and in social contexts which stand outside the health care setting. For example, in the context of the current study, the narrative elements of participants' accounts are linked to the

various stages and perceptions of the illness; some participants portray epilepsy as a journey or a transition in which lessons have been hard earned, while others view it as an end in itself. As such, stories reflect both changes in identity and in perception over time.

2.5.3. Narrative inquiry as a means to addressing the gap in epilepsy research

To date the focus of epilepsy research has been on symptom measurement and on direct comparison of difference across various 'quality of life' domains experienced between cohorts of people with epilepsy and so called 'normal' populations. Findings from these types of study quantify experience into possible trajectories that fit within a medical model of (i) understanding/documenting symptomology and clinical outcomes, and (ii) identifying subsequent treatment regimes. Such approaches are limited in that their generalised assumptions about common patterns within the epilepsy trajectory relate to groups of patients rather than to individuals (Jacoby, et. al, 2004). Thus the subjective experience of the individual is obscured (Elliott et. al, 1999; Andermann, 2000).

However, the number of qualitative studies of the experience of living with epilepsy in adulthood has seen an increase in recent years; enabling a range of individual experience to be explored, both within and between individuals. Raty and colleagues (2009), for example, identified the meaning of epilepsy as a concept to be varied, ranging from epilepsy as an illness related to physical disturbances to epilepsy as a handicap in relation to associated psychological and social implications. Not unexpectedly, the investigators reported that emotions associated with epilepsy varied with the meaning of the illness to the person. This highlights the varying meanings that the illness can hold and the impact of meaning upon a person's understanding and experience. Similarly, Faircloth's (1998) study of three epilepsy narratives sought to highlight the diverse nature of the epilepsy experience, while Nijhof (1998) spoke of the heterogeneity of interpretations within individuals; arguing that individuals make multiple interpretations of their experience, which change over time. Nijhof (1998) found that the medical discourse was often seen close to the period of diagnosis, but that most people distanced themselves from this after a period of time. Concepts of normality or abnormality appeared to be linked to whether the individual was talking of interpretations of the self or of others; highlighting the social nature of the epilepsy experience. However, Andermann (2000) notes that the studies of Faircloth (1998), Nijof (1998) and Raty, et. al (2009) while highlighting the range of experiences neglect to focus upon the context in which the narrative is situated. Thus it is difficult to

translate the study outcomes and methods employed in these studies directly to my own study.

The role of family and cultural narratives in understanding experience was highlighted by Good and Good (1994). Again it is not possible to draw direct conclusions from this study and apply them within the context of people living with epilepsy within the UK, as the researchers explored narratives of individuals and their families in Turkey. However, this study did highlight the multiplicity of perspectives held by people with epilepsy and their families and how these perspectives may be influenced by cultural beliefs about healing and epilepsy and the need for continued care-seeking as a mechanism for maintaining hope.

A more recent study conducted by Small and colleagues (2005) set in Bradford's South Asian community highlighted the range of understanding of epilepsy held within this community. Individuals' understanding shaped their management and disclosure and was related to a multiplicity of beliefs, often with Western narratives of causality existing in tandem with spiritual narratives. While the context of Small's (2005) and Good and Good's (1994) study are not directly comparable to my own study group they nevertheless highlight the complex relations and understandings of epilepsy that impact upon a person's understanding, their experience of living with the condition, and their access to health care. They are also extremely valuable in developing clinical understanding of beliefs and their role in health behaviour.

As evident in section 3.4, the role of societal, historical and cultural narratives of epilepsy, in particular stigma and its impact upon individual experience, has also been explored both qualitatively and quantitatively. In a qualitative study, Kilnic & Campbell (2009) focused upon the experience of epilepsy from diagnosis onwards. Three themes emerged; misconceptions versus ownership, avoiding versus sharing and embarrassment versus normalising. These findings resonate with early studies of stigma (Schneider & Conrad, 1980). Conversely, Admi & Shaham's (2007) study portrayed a different perspective to the dominant narrative of stigma and epilepsy, advocating for a normalcy model; that of "*ordinary people living with extraordinary circumstance*" (p.1187).

Although research on illness narratives exists, the narratives of people with epilepsy, with few notable exceptions, are sparse. The studies mentioned within this section highlight the ability of in-depth qualitative research to foreground the subjective and different

experiences of those living with epilepsy. Illness narratives, offer valuable insights into the experience of living with illnesses and highlight that the person's experience is more than their symptomology. However, narratives need to be considered within context. This includes the way in which the narrative is told, as well as a consideration of the immediate and wider context in which the narrative is situated (Riessman, 2008). All the studies cited above are set within different cultures and employ different methodologies. They also neglect to focus on why a story may be constructed in a particular way and the rhetoric individuals engage with in order to perform a particular narrative within a given research context. By overlooking this important function of narrative, information crucial to understanding the experience of living with epilepsy, its meaning to the individual, and how it is managed is lost (Brosh, 2011). For this reason the current study focuses both on 'what' is told and 'how' it is told and I argue this is critical in order to widen our understanding of epilepsy experience, and how meaning is constructed, which will ultimately inform knowledge through detailing local context.

2.6. Research methods

In section 2.5, I sought to demonstrate the various ways in which narrative inquiry can facilitate thinking about and communicating chronic illness experience such as epilepsy. Evident in this literature is the diversity of approaches to and uses of narratives as a form of qualitative research, and the eclectic perspectives adopted by the narrative researchers. This diversity is inevitable (Squire, 2007) and indicative of the fact narrative does not have a single heritage or methodology (Emden, 1998). The vast literature on narrative covers almost every discipline and profession including, for example, history, sociology, anthropology, psychology, medicine and therapy (Labov & Waletsky, 1967; Propp, 1968; Bertaux, 1981; Bury, 1982; Bruner, 1986; Mishler, 1986a; Robinson & Hawpe, 1986; Sarbin, 1986; Brody, 1987; Kleinman, 1988; Polkinghorne, 1988; Coles, 1989; White & Epson, 1990; Rosenwald & Ochberg, 1992; Freeman, 1993; Riessman, 1993; Younger, 1995; Hyden, 1997; Greenhalgh & Hurwitz, 1998). Similarly, this narrative inquiry draws on a number of qualitative traditions; it is phenomenological in nature, using elements of grounded theory, social constructionism and narrative analysis to understand the data collected.

My purpose within this section then is to highlight the theoretical influences that have guided my own narrative approach within the context of this study and to detail the application of these methods as a means to providing a structured, iterative and transparent process for exploring the experiences of individuals with epilepsy. I will also

detail the strategies employed to ensure participant involvement and consistent contact throughout all the stages of recruitment, data collection and data analysis.

2.6.1. Theoretical influences guiding my narrative approach

In his Actual Minds, Possible Worlds, Bruner (1986) outlines two distinctive modes of thought or ways in which we come to know the world; assigning the traditional (logical-scientific) mode of knowing as paradigmatic cognition and storied knowing as narrative cognition. As an extension of Bruner's (1986) work, Polkinghorne (1995, 1988) identifies two modes of narrative inquiry which I have followed in order to systematically address the various aspects of my data collection and analytic process. To aid my thinking around how narrators give meaning to experience I have also given consideration to the work of narrative theorists Frank (1995) and Bury (2001). While their analytic approach differs, both provide theoretical frameworks (narrative plot) to aid the examination of how illness unfolds over time. Lastly, within this section, I discuss the varied distinctions, in the literature, between the terms 'story' and 'narrative'; how story and narrative distinctions function as meaning making devices, and, make explicit my own distinctions within the context of the present study.

2.6.1.1. Polkinghorne's two modes of narrative inquiry: paradigmatic and narrative

Before discussing the analytic process in detail (see section 2.6.3) it is useful to establish here necessary explanations of narrative inquiry as described by Polkinghorne (1988). Firstly, Polkinghorne enabled me to focus my research approach as a '*descriptive*' one - as opposed to an *explanatory* one – whereby, *'an accurate description is produced of the interpretive narrative accounts individuals or groups use to make sequences of events in their lives or organisations meaningful'* (p161). This involves description of life stories and / or specific life events, the circumstance under which a particular storyline or plot prevails over or conflicts with another, the relationship between an individual's story and existing cultural stories and the function that certain life episodes serve in the individuals' 'emplotment' of their lives. (Sandleowski, 1991).

Two modes of narrative inquiry are identified by Polkinghorne (1995, 1988), both of which I have followed within the conduct of this study. The first mode - paradigmatic analysis of narrative – *'searches for universal truth conditions'* (1988, p17) and moves from stories as a unit of analysis to common themes that cut across the stories, characters or settings to

produce general concepts. This can be done deductively by applying theory to the data, or as in the case of the present study, inductively by allowing themes to emerge and concepts to develop from the stories. The second mode of analysis is narrative analysis which uses plot to connect individual experiences in order to create the context for understanding meaning. The outcome of this process is a narrative or set of narratives developed through the interpretation of stories via the use of a plot in order to give meaning to experience. The strength of paradigmatic analysis lies in its capacity to develop general knowledge but it can be abstract and formal; whereas narrative analysis provides insight and understanding about the people being studied (Oliver, 1998). For this reason I decided to use a combination of both approaches. I begin with a paradigmatic analysis of the narratives, conducted across all the interview transcripts. In addition to this, narrative analysis is employed to produce a set of stories facilitating deeper insight and understanding into how my participants gave meaning to experience in the construction of epilepsy narratives. I argue therefore, that my dual approach to analysis offers a means by which to elucidate interpretations of the data that may otherwise escape consideration with the use of a single approach.

2.6.1.2. Giving meaning to experience

Frank (1995) discusses three types of 'narrative plot' which provide a useful theoretical framework for understanding the different ways in which individuals tell their illness narratives. Two types, the 'restitution narrative' and the 'quest narrative' provide patients with positive meaning for the illness experience and can be viewed as positive coping stories. The third type, the 'chaos narrative' carries no such meaning and, as such, might impede patients coping with illness. For example, the restitution narrative is essentially a story about health. The sequence of the plot situates the narrator as one who was once healthy, is now sick, but will soon return to being healthy. By articulating restoration of health as a goal, this narrative type reaffirms the normative nature of health. The quest narrative portrays illness as a journey, an experience from which something can be gained or learned. Here the narrator is a hero whose illness is simply a journey (Campbell, 1968) beginning with 'departure', the symptom of bodily disorder; followed by 'initiation', in which the narrator crosses the boundary of the world of the healthy into the world of the sick; and, ending with 'return', at which point the narrator becomes knowledgeable about both these worlds. At the point of return, the narrator, according to Frank (1995) is *"no longer ill but remains marked by illness"* (p118). Conversely, the plot of chaos,

characterised by a lack of narrative order and causal links is a plot which provokes anxiety - articulating a future in which the narrator cannot regain prior health status and assigns negative meaning to the illness experience. In contrast to the narrator of the restitution narrative who is confident, the narrator of the chaos narrative is vulnerable and lacks any sense of control. Illness is perceived as a disaster.

Bury (2001) distinguishes three types of illness narratives that are distinct, but also can be employed alongside each other and are shaped by purpose and context. First '*contingent narratives'* comprise those aspects of the person's story surrounding beliefs and knowledge about the factors that influence the onset and early course of a disorder, and its immediate or *'proximate'* effects on the body, self and others (p268). Contingent narratives often outline the steps taken to deal with the illness and the strategies employed to manage its effects. Such narratives tend to be descriptive in nature, dealing with events as they unfold. Second, *'moral narratives'* move the account from descriptive to evaluative in that individuals seek to account for and perhaps justify themselves in the altered relations of body, self and society brought about by their illness (p274). In dealing with biographical reconstruction individuals may present themselves as culturally competent. Narratives in this sense not only assist in the ordering of experience but also help to express the dynamic relations between self and others. Bury highlights that moral narratives may include social apologia in which the person attempts to narrow the gap between their previous self-image and what they perceive or encounter as failures in self-presentation or role performance. Conversely, moral narratives may also be a means to portray oneself as active and engaged. This brings us to the third of Bury's narrative forms, *'core narratives'*. These can be considered as the presentation of one's identity through *'genres of expression'* in which the narrator *'emplots'* themselves in a more or less dramatic fashion. For example narratives may be epic, tragic, comic or didactic; the latter serving to allow people to account for events and to give shape to them in terms of the way in which they relate to self and others (p278-279).

Core narratives may also convey the underlying trajectory of the illness and the feelings associated with it. In this regard Robinson (1990), drawing on the earlier work of Gergen and Gergan (1986) was able to demonstrate how illness narratives of participants with multiple sclerosis may convey progressive (a move towards personally valued goals), stable (sustain the same position in relation to personally valued goals), or regressive (move away from personally valued goals) qualities. Progressive narratives portray a positive and more

engaged response by the individual, and resonate with a postmodern culture surrounding illness posited by Frank (1995); one of restitution where the search for a more positive identity through suffering may be found. Robinson (1990) asserts that *'stable narratives'* are *'less engaging'* (p1178) as they tend to be less dramatic – a form of storytelling which has been alluded to above as contingent narrative. The regressive narrative portrays a continual discrepancy between valued personal goals and the possibility of their attainment. In their extreme form, Robinson (1990) notes, regressive narratives portray tragic accounts.

2.6.1.3. Defining narrative and story

Within the literature, the terms 'story' and 'narrative' are problematic as each is defined variously and used interchangeably. By way of example, Polkinghorne (1988), considers the terms to be equivalent; defining narrative as *"the kind of organisational scheme expressed in story form"* (p13), while Riessman (1993), concludes "*that most scholars treat narratives as discrete units, with clear beginnings and endings, as detachable from the surrounding discourse rather than as situated events"* (p17). Frank's (2000) position is that people tell stories, but narratives come from the analysis of stories. This distinction, according to Riley and Hawe (2005), relates to where the primary data ends and where the analysis or interpretation of that data begins.

Narrative also pays attention to the context of storytelling, to the real and assumed audience of narratives, through the individualised narrative situation of research interviews. This is consistent with Mishler's (1986a) position that highlights the micro-contextual, co-construction of narrative, emphasising the importance of the relationship between the 'teller' (research participant) and the 'listener' (researcher). Qualitative research in general is of course often reflexive about contextual processes, but such considerations are embedded in narrative research; the notion of 'story' always entails 'audience' as well as 'storyteller'. In this regard narratives located within an interview structure draw on the 'tellers' position within their social world but will inevitably be influenced by the skills and professional orientations of the interviewer as 'listener'. As Bruner (1990) comments narrative analysis has to do with *"how protagonists interpret things"* (p51) and how we then systematically interpret their interpretations. It follows then that any distinctions I make between story and narrative need to be defined and articulated, for they frame both the process and the product of my analysis.

In the context of this study, I define s*tory* as discrete actions or events that are topically specific and organised around characters, setting and plot but conceived as independent of the surrounding discourse. I define *narrative* as the discursive presentation of events, which may not always be evident to the teller but analytically requires I pay attention to:

- Talk that is not about events but that still carries significance for the teller's story of who they are;
- How the teller temporally and spatially structures the narrative, for example, how they look back and recount lives that are located in particular times and places;
- How the narrative draws on surrounding cultural and political narratives to shape meaning and understanding;
- The structure of the spoken language, for example, contradictions and gaps, stories implied but not told; and, the interaction between the story teller and the listener in the co-construction of stories.

Thus, viewed as a meaning making device, a narrative gathers individual objects, actions and events into an understandable pattern; telling a story turns available parts into a meaningful whole (Gubrium & Holstein, 1997).

2.6.2. Respondent recruitment and data collection

2.6.2.1. Locating the sample

The participants for this study were recruited from two adult out-patient clinics for people with epilepsy located at a regional centre for neurology and neurosurgery in Liverpool. Access to this patient population was negotiated via the medical consultant of each potential participant, who acted as gatekeeper during the initial phase of the recruitment. Participants were selected using purposive sampling, an iterative and sequential process informed by Miles and Huberman's (1994), qualitative sampling plan checklist. Due to the busy nature of the clinics it was not possible to keep a record of the number of patients approached by each of the consultants or to identify the number of patients who declined to be introduced to me, in order that I might explain the study further. However, both male and female adults were considered eligible to participate in the study if they were aged 18 years or over; had received a confirmed clinical diagnosis of epilepsy made no less than two years previously – the purpose of this time frame being to ensure that all participants had a history of life-experience as a person with epilepsy.

As a means to achieving breadth within the sample, no exclusions were made on the grounds of marital status, ethnicity, or socio-economic background. To ensure diversity across potential participants, this process was informed by the literature on epilepsy, for example those variables identified as having an impact on an individual's clinical condition and their perception of quality of life. These variables include; age, gender, etiology, age of epilepsy onset and duration, and seizure type, duration and frequency (Jacoby 1992; Jacoby etal. 1996; Baker et al. 1997; Ratsepp etal. 2000; Dilorio etal. 2003).

Approvals to conduct the study were obtained from the recruiting NHS Hospital Trust Research Governance Committee - RG No: 013/05 and from the Liverpool Central Research Ethics Service (Northwest REC2) - REC No: 08/H1005/45. It was agreed with the Local Research Ethics Committee that individuals would be excluded from the study on the following grounds of participant vulnerability: under the age of 18 years; currently receiving clinical treatment(s) other than anti-epileptic drug therapy, for example epilepsy surgery or vagus nerve stimulation; diagnosed with a mental illness or learning disability; participating in another research study; or, unable to provide informed signed consent to participate. The narrative nature of the study design meant that opening up recruitment to non-English speaking participants was potentially problematic with regard to language and associated interpreter and translation costs. Therefore, on the grounds of limited financial resources, ethics committee approval was granted to exclude individuals who were unable to understand or converse in English.

2.6.2.2. Pilot study phase

The ultimate size of the sample was difficult to estimate in advance. Consideration needed to be given to ensuring the collection of sufficient data in order to reflect depth and diversity of the phenomenon whilst not having so much as to render the study unmanageable (Kvale, 1996). For this reason, and following lengthy discussions with my academic supervisors and other senior qualitative research colleagues, it was decided to initiate a pilot study phase which would involve the recruitment of six participants. This process, together with a review of the quality of the data collected was discussed further with my research colleagues prior to making a decision regarding the number of participants to be recruited.

During the pilot phase it became evident that though a considerable number of potential participants would be able to meet the study criteria, the sensitive nature of the research

topic meant many would not wish to become involved. A comparison of the transcripts of the six participants who had agreed to be interviewed highlighted a number of differences in the type of data collected. For instance the interviews varied both in focus and depth; in the case of one participant I was unable, at first interview, to elicit little more than descriptive accounts of specific events and situations, whilst other participants were able to talk in great depth, and displayed an ability to reflect on past events and verbalise their thoughts and feelings. Discussions with colleagues led to consensus that this ambivalence in participants' narrative content and form was a reflection of the research encounter. Their stories are autobiographical reconstructions; this is the narrative approach. Re-focusing our discussions on my research questions (as outlined in section 1.3.) enabled confirmation of the appropriateness of this approach in securing data (albeit limited at this stage) that held the potential to answer these questions.

As anticipated a considerable amount of time was invested in developing and maintaining a research relationship with my participants. This process involved meeting with potential participants for preliminary discussion (lasting up to approximately two hours), returning to participants to undertake tape-recorded interview, (lasting up to approximately three hours), and subsequent encounters including for instance, written communications, telephone conversations and data verification. Therefore, for pragmatic reasons relating to time, resources and the anticipated data to be generated, it was considered appropriate to limit study participants to between twelve and fourteen. In the event sixteen participants were recruited, two of whom withdrew prior to interview (for personal reasons unrelated to their clinical condition); therefore the total number of study participants was fourteen.

2.6.2.3. Eliciting stories

The initial approach to all potential participants was made via their medical Consultant who acted as gate keeper and provided an information pack (containing a letter of introduction and written details regarding the nature and purpose of the study) for consideration. Potential participants who expressed an interest in participating and who agreed to being contacted directly by me were then telephoned.

I made arrangements to meet with each individual by telephone, which acted as an early opportunity for me to begin developing a relationship with the participants. I offered to conduct the interview either within the participant's home or at an alternative venue of their choice. Twelve participants requested the interview within their own homes, one

participant chose to meet at work and I met one participant in a restaurant. The purpose of this preliminary interview was twofold. Firstly, it provided an opportunity to meet participants informally prior to conducting the formal interview and by adopting a respective, non-patronising position I hoped to minimise any nervousness they might be experiencing. Establishing good rapport with participants was also crucially important; sharing details about my own personal and professional background, the research and an expression of interest in the individual experience of each participant would enable me to promote trust and to verbalise my intent to protect them from any unintentional anxiety or stress that might arise through exposure of their vulnerabilities. Secondly, this meeting enabled me to fully discuss the consent process and the use of the tape recorder and to obtain the signed consent of individuals wishing to participate.

A second meeting to conduct the tape-recorded interview was then arranged with each participant. In most instances, participants chose to be interviewed at the same location at which their first interview had taken place. One participant chose to be interviewed at the home of a friend and I met a further participant in a private room at the university.Thus, the majority of the interviews were conducted within an environment familiar to the participants. From a research perspective this situation has the advantages of disempowering the researcher, who finds herself on unfamiliar territory; and increasing the authority of the participant. Interviews held within the home also facilitate researcher insight into contextual factors and home circumstances. However, I am mindful that the request of one participant to conduct the interview within the university setting carried two key disadvantages. Firstly, it privileged my own authority as the researcher and potentially risked reducing the participant to a subject, so inhibiting the elicitation of narratives; and secondly, the environment itself was less conducive to facilitating contextual insight. However, by demonstrating my empathy and understanding I hoped to develop a reciprocal relationship with my participants which would promote trust, honesty and openness and in doing so seek to neutralise the potential for any imbalance of power between us.

As an established social science technique, the interview is one of the main data collection tools in qualitative research (Punch, 1998). I conducted in-depth, face-to-face interviews with men and women with epilepsy with the purpose of eliciting personal stories told in their own words. As such, the interview approach provided a powerful medium through which to enhance understanding of others. As Jones succinctly puts it:

> *"In order to understand the other persons' constructions of reality we would do well to ask them…and to ask them in such a way that they can tell us in their terms . . . and in a depth which addresses the rich context that is the substance of their meanings"* (Jones, 1985, p46).

The narrative format of a life story allows the interviewee to speak with relative freedom (Nijhof, 1998). For this reason, no formal pre-determined questioning was employed during the conduct of my interviews and the answers were not pre-constructed. Rather my participants were invited to tell their life story to demonstrate the social and psychological experience of their epilepsy and the meaning that they attached to this experience. During my encounters with participants I remained mindful of the need to provide a facilitating context to enable interviewees to tell complete stories about important moments in their lives (Mishler's 1986a). Thus, my primary task as listener was to discover the interviewee's own framework of meaning and to avoid imposing my own structures and assumptions, in as far as possible (Britten, 1995).

Notwithstanding my theoretical stance, I was required by the Local Research Ethics Committee to design and submit for approval an interview guide[3], which I developed to provide initial contexts. Following Riessman's (1993, p55) advice, I devised seven broad categories about the topic of inquiry. These included an introductory phase, clinical manifestations of the condition, health seeking process, daily life circumstances and activities, perception of role within society and relationship with others, perception of self in relation to epilepsy – past, present and future, and, coping strategies employed. Each category was supplemented by probe questions to assist my participants in providing more focused, deeper and detailed information based on their told story. During the ethical review process I emphasised to the committee that the interview guide, would be used only as a conversational agenda rather than a procedural directive (Holstein & Gubrium, 1995).

I began each interview with an introductory statement:

> *"We hear a great deal about epilepsy in terms of its medical management but far less perhaps about how the condition affects the daily life of a person with epilepsy from the point of view of a person with epilepsy. This is why I am interested in hearing your story of your life with epilepsy…"*

[3] See Appendix 2: Interview Guide

The purpose of this introduction was to promote my interviewees' sense of competence in participating in the interview and to assure them that what they had to say was of interest and would accomplish something useful. This was followed by asking the participant to:

> *"Tell me the story of your epilepsy from the moment you realised or were told that something was wrong with you, even if those events were not formally defined as epilepsy"*

This request provided direction for the conversation and acted as a 'signpost' to guide my participants through their experience (Holstein & Gubrium, 1995). Their story(ies) might follow a chronological sequence and should enable them to discuss key events. As listener I needed to clarify uncertainties with follow-up questions and I used the responses given by participants to continually inform the evolving conversation (Paget, 1983). Thus, the use of the guide varied from encounter to encounter, and only as appropriate to engage my participants and develop narrative territory.

2.6.2.4. Continuing links

As recommended by MacDougall and Fudge (2001), consideration was given to how best to maintain relationships and contact with my participants throughout the process of this qualitative inquiry. I initiated a number of strategies: an annual research newsletter[4] outlining the progress and future steps involved in the study; together with an overview of associated activities, including for example, conference presentations and publications was mailed to all my participants. I returned to participants to provide them with an opportunity to comment on the analysis and their experience of the research process. Copies of published papers associated with the research and a copy of the lay report of the findings were posted to those participants who had expressed interest in reading them. I also had follow-up telephone conversations with several participants; Brenda, for example, called to tell me of a writing group she had joined and how this activity was helping her to come to terms with her enforced early retirement from work.

[4] See Appendix 3: Example Research Study Newsletter

2.6.3. Data analysis

2.6.3.1. Analytic process

The qualitative research software programme NVivo (Bazeley & Richards, 2000) was used as a management tool throughout the research process. The purpose of this undertaking was to provide a transparent account of my work and insure a rigorous approach to data analysis. The interviews were transcribed verbatim using a selection of transcription conventions to indicate emphasis, pace, pauses, volume and emotion, unintelligible words and false starts. I also transcribed my field notes and personal memos. This raw data was then imported into the NVivo programme. The powerful search facilities of this software enabled identification of key words, phrases and attributes from across the data set and allowed me to examine the data from a number of different perspectives. Nodes[5] were created to mark relevant concepts and topics in the text documents. An account of the process of analysis was logged in the memos attached to categories and interview documents, including the questions used to interrogate the data, and my thoughts and decisions about what themes to focus on.

The analytic techniques employed in this study are described below separately and are arranged in a sequence that follows through from the beginning to the end of the process. In practice however, it was necessary to move back and forward between these steps; also some of the techniques described here as discrete occurred simultaneously. Throughout I sought to verify my interpretations through discussion with others, including my supervisors, fellow researchers, and at postgraduate workshops, university seminars and external conferences. These discussions proved important in so far as they offered fresh insight – personal, professional and cultural – enabling me to usefully reflect on my personal biases and assumptions.

2.6.3.2. Reading and immersion

Familiarity with the material was developed through slow, careful and repeated reading. Within a few days of conducting each interview I listened to the audio-tape(s) and took notes on what seemed significant. As I received the completed transcripts, I read each one carefully and then listened to the tapes again as I read over the transcripts. I repeated this

[5] See Appendix 4: NVivo Nodes

process a number of times, summarising significant events and themes of interest after each reading session; a process similar to 'memo-ing' in grounded theory (Glaser & Strauss, 1967).

2.6.3.3. Paradigmatic analysis of narrative

Polkinghorne's (1995) paradigmatic mode of analysis requires each transcript to be individually coded for content and themes. This procedure involved detailed, systematic, line-by-line coding, consideration of how the codes might be meaningfully clustered together to develop categories and concepts, and the subsequent development of themes. No *a priori* coding scheme was used; instead *a* bottom-up approach was employed, using only concepts and categories generated by the data. The use of 'open coding' ensured that concepts and categories were grounded in the data and that any theoretical concepts to be used had earned their conceptual status – akin to grounded theory analysis (Glaser & Strauss, 1967).

According to Coffey and Atkinson (1996), qualitative coding is *primarily* a way of interacting with and thinking about the data. Of central concern therefore was how should I recognise and construct a theme and how to determine what was important enough to discuss and what was not. To enable consideration of both process and meaning (Savage, 2000) my search for themes was underpinned by various identified *features of significance* (Love, 1994). These included: repetition within and across interviews; levels and nature of affect, including emotional, vocal and bodily expressions that leant significance to the content or theme when noted concomitantly; stories from the past that leant significance to present behaviours and meaning; explicit and implicit interpretations and consideration of the connections between thoughts and activities and the meaning attributed to them, whether direct, implied or metaphoric; and, expressions and beliefs of participants that were different from what might be expected based on my own reading and experience.

2.6.3.4. Narrative analysis

The process of narrative analysis takes us beyond the content of the stories to examine the way in which the story is ordered, the linguistic and cultural resources it draws on, and how it persuades the listener of its authenticity (Riessman, 1993). The outcome of this process as described by Polkinghorne (1995) is a narrative or a set of narratives which give meaning

to experience. To assist in the application of a narrative analysis as described by Polkinghorne (1995), the following criteria need to be met:

- A description of the cultural context.
- Identification of the nature of the protagonist – both physical and cognitive.
- Identification of important significant others in affecting actions and goals for the protagonist.
- Concentration on the choices and actions of the main character in pursuit of particular goals.
- Attention to previous experiences as these manifest themselves in the present.
- Production of a story with *'a bounded temporal period; that is a beginning, middle and end'* (p17).
- Production of a story line or plot that serves to configure or compose the disparate data elements into a meaningful explanation of the protagonist's responses and actions' (p17).

So, this process begins with the identification of stories within the text.

2.6.3.5. Identifying stories

As I read through the interview transcripts, I found that determining the beginning and end of a story segment was not always a straightforward procedure. This was because my participants did not always tell stories in a structured way (Labov, 1972). Rather, they told stories across interrelated themes, where the point was not always immediately obvious. I also noted that my participants' evaluation of events occurred, not as Labov assumes (Reissman, 1993), as a discrete, secondary structure related to causal sequence, but as continuous and embedded. Evaluation, for many of my participants, was an integral component of the narrative process which served to facilitate a particular presentation of their identity. For example, in the narrative of one participant, Brenda, evaluation was used to emphasise shifting attachments across familial and working roles and her revised expectations of both when questioning her adequacy as competent mother and worker.

To enable me to take account of these early impressions of my participants' narratives, I decided to use Mishler's (1986b) analytic framework of 'core narrative' (see Figure 2). While the four story components of orientation, abstract, complicating action and

resolution draw on Labovian analytic theory, Mishler's (1986b) framework focuses less on the relationship of linguistic structures and in so doing brings into focus the relationship of teller and listener. In the current study, my intention was to elicit an illness narrative reflecting the life-world of the patient and not different biomedical explanations of epilepsy. To this end Mishler's (1986a) emphasis on the interview as discourse and how different types of interviews can facilitate or hinder respondents' efforts to make sense of what is happening to them bears relevance to my own research endeavour. My argument here is that the effort to empower respondents and the study of their responses as narratives are closely linked. These methodological and philosophical preferences require a rich description of the research setting and the individuals participating in it; if knowledge is socially constructed then an account of the relationships and the contexts within which meaning is ascribed is vital.

For this reason, identified stories, that met Mishler's (1986b) categories of core narrative as outlined in Figure 2, were re-transcribed in greater detail to highlight some key features in form.

Figure 2: Mishler's Core Narrative Framework

Category	Description
Orientation (O)	Describes the setting and the characters
Abstract (A)	Summarises events or incidents of the story
Complicating Action (C)	Offers an evaluative commentary on events, conflicts and themes
Resolution (R)	Describes the outcomes of the story or conflict

(Mishler, 1986b)

For example, Figure 3 provides detail of a coded story identified in text as told by Brenda. Here she describes the occurrence of a nocturnal seizure and her subsequent action to resign from work:

> *"I never slept in on me own. It was always a team of us because we had 12 children to look after. Err and they were split up into groups so err, err, but then I had, I got moved to a smaller unit with 9 children in and err it was one, one night…I mean, I'd had a couple* [seizures], *but not were it would finish me job, if you know what I mean, and like I say they did know about it* [having epilepsy]. *Erm…but this particular time you slept in and you slept in on your own. I had, had a seizure that one night when I was on duty. Erm, I wrecked me room. I must have been walking, sleep walking, it was wrecked erm…and so… the boss was brilliant. But, instead of him having to finish me I decided to say, coz I knew that it would have to, I wouldn't be able to work in that erm … home again, so I said well I'll, I'll finish. And err… so that was that and I were there for about 5 years".*

Looking at the form of this story we can see that it has all of the structural components of Mishler's (1986b) core narrative. It sets out the setting and characters (lines 01-02), contains a core plot / abstract of events (lines 03; 06-08; 10) resolved by Brenda's action (line 10). Brenda's closing comment (line 11) signals the end of the story. However, while including an evaluation of events (lines 04-05; 07-08; 10) this story leaves us with questions unanswered. For instance, why did Brenda resign her position and what led to Brenda's understanding that she would not be able to work in the children's home again? It was not until I responded to Brenda's story by creating an opportunity for its further elaboration that this discrete story and Brenda's subsequent elaboration could be seen as a 'new whole'.

Figure 3: Identifying a story using Mishler's (1986b) Core Narrative Framework

Line	Story Text: ***"I wrecked me room"***
01	I never slept in on me own **(A)**
01/02	It was always a team of us because we had 12 children to look after **(A)**
03	I got moved to a smaller unit with 9 children **(O)**
04	I'd had a couple [seizures], but not where it would finish me job **(C)**
05	And like I say they were, they did know about it [epilepsy] **(C)**
06	this particular time you slept in and I slept in on me own **(O)**
06/07	I had a seizure that one night when I was on duty **(O)**
07	I wrecked me room **(O)**
07/08	I must have been up walking, sleep walking **(C)**
08	It [room] was wrecked **(O)**
08	the boss was brilliant **(C)**
08/09	instead of him having to finish me - I knew I wouldn't be able to work in that home again **(C)**
10	I said well I'll, I'll finish **(R)**
11	that was that and I were there for about 5 years **(C)**

2.6.3.6. Storyline or plot development

It is *plot,* Polkinghorne (1988) asserts, which provides stories with the potential to bring meaning to people's lives. *Emplotment* is the process of working with one or more plots of a story to elicit its significance; emplotment ascribes sense to a story. Therefore, analytic consideration was given to the form and direction of the story content and to the dynamics of the plot – implied for example by various speech events including reflections and evaluations, turning points, future aspirations and objectives.

So, returning to Brenda's account by way of example, her subsequent evaluation of events enables us to view her narrative re-construction as a 'new whole' which incorporates the

'moral' components of experience. The story form shifts from one of 'contingent narrative' to 'moral narrative' (Bury, 2001); one that involves evaluations of how individuals account for themselves in altered relations with others and society brought about by illness – a concept explored further in Chapter Six. Brenda's work-related narrative is consistent with this view, in that she uses her evaluations to explain and justify her actions so as to allow her to present herself as a *"morally competent actor"* (Pinder, 1995, p624).

2.6.3.7. Member checking

The final stage in the process of analysis involved returning the core story to participants for verification and discussion to answer the question of – does the story ring true?

2.6.3.8. Presentation of results

In presenting my findings I have chosen to use a number of writing strategies to reflect both process and outcome in the interpretation of my participant's stories; these include: verbatim sections of text, defining features of a story, summary descriptions and representations and the use of core stories. This approach is driven both by my concern to present credible evidence to enable academic scrutiny and by the desire to illustrate how narrative has the ability to reflect personal illness experience in everyday life.

2.6.4. Ethical considerations

The ethics of narrative inquiry can be said to revolve around the fact of being in relationship with others, which brings with it responsibility and accountability especially with regard to the process of data collection, and the role of the researcher within that process (see for example, Oleson, 2000). Thus, at every stage of this research – from its original formulation to the re-presentation of participants' stories – I made a conscious effort to empower my participants and position them as experts on their experience. This required me to consider how fragile and in need of negotiation my relationship with each participant was, and the need to acknowledge the importance of reciprocity with in that relationship (Clandinin & Connelly, 2000). In practice this meant learning how to listen and receive stories, and to respond with interactions of genuineness and respect. It meant treating my participants with dignity and searching for *their* meanings and understanding *their* actions as *they* saw them. However, whilst actively seeking to involve my participants in the meaning-making process, I remained mindful that researchers occupy a more powerful position because

they frame and write the accounts, interpret and bring new meaning to the interview material (Gergen & Davis, 2003).

This study was designed, approved and conducted in accordance with NHS Research Governance Framework for Health and Social Care (2nd Edition) guidelines (Department of Health, 2005). It is recognised that qualitative research of the type reported here may involve an element of emotional risk to those participating. Due consideration therefore was given in the design of the research to issues surrounding informed consent, maintenance of anonymity and confidentiality, psychological distress, and power relations and deception. These potential areas of risk, together with an explanation of the strategies implemented to reduce their occurrence were made explicit in the research proposal and explained clearly to my participants.

Acknowledging that qualitative data by its nature may contain multiple clues to an individuals' identity (Richards & Schwartz, 2002), particular emphasis was placed on the protection of all participants in relation to the informed consent process and the maintenance of confidentiality and anonymity.

2.6.4.1. User involvement in the research design and process

In line with INVOLVE Group guidelines, Briefing notes for researchers: Public involvement in NHS, public health and social care research (INVOLVE, 2012), this project sought to support active user involvement in its design and focus, thus promoting user consultation, collaboration and control. I outline below the mechanisms employed for achieving this:

- Findings from a previously conducted consultation on the position of people with epilepsy were used to underpin the focus and design of this study. This involved consulting people with epilepsy, their family members, and their carers who were members of The Mersey Region Epilepsy Association. This process, aimed at gaining 'insider perspectives', assisted in contextualising the issues of epilepsy stigma, lay attitudes towards epilepsy and the terminology used for discussing epilepsy.

- Professor Gus Baker, in his capacity as Vice President of The Mersey Region Epilepsy Association, was asked to review the study proposal. His comments supported the appropriateness of the project design and objectives, which focus on individual and user perspectives.

- Successful applications for ad hoc funding support were made to Epilepsy Action and to the International Bureau of Epilepsy. Both these organisations provide opportunities for people with epilepsy to get involved in research and such funding

support is dependent on a favourable review by a network of lay volunteers to ensure that the research is relevant and important to people living with epilepsy.

- Ongoing collaboration was achieved through the narrative format of a life story which allows the interviewee to speak with relative freedom. Interviewing is inherently collaborative; with both interviewer and narrator working together to actively construct a story and its meaning. This collaboration continues throughout the data analysis period as interviewees are invited to become involved in their own data interpretation and verification. This perspective empowers respondents - they are not merely subjects of research but better seen as narrators and co-researchers in the process.

2.6.4.2. The informed consent process

To enable potential respondents to give free and informed consent, oral and written details relating to the purpose, extent and implications of their involvement was provided. In line with COREC (2001) recommendations, a letter of introduction[6] together with a comprehensive information sheet[7] was devised which outlined the study in detail, together with my contact details to enable those with an interest to seek further information and advice should they wish to do so. The consent form[8] was developed using the same recommendations; potential participants were given an opportunity to ask questions, understood their participation was voluntary, and, were informed they were able to withdraw from the study at any time without their clinical care being affected. In addition, each respondent's GP was informed of their participation via a letter of introduction to the research[9] and also received details outlining the purpose of the study.

2.6.4.3. Maintaining participant anonymity and confidentiality

To maintain patient confidentiality during the early phase of recruitment, access to study participants, together with specific details of the nature of the researcher role was negotiated via the patient's hospital Consultant. Use of the tape recorder and the process for disposal of notes, transcripts and tapes was discussed with participants. Written consent included permission to tape-record the interview, and participants were given the opportunity to comment on the validity and reliability of the transcript. Confidentiality and anonymity was assured and my participants were advised that all information obtained during the study would remain confidential, with secure storage of tapes and transcripts.

[6] See Appendix 5: Participant letter of introduction
[7] See Appendix 6: Participant information sheet
[8] See Appendix 7: Participant consent form

[9] GP Research information letter is available to view on request

Pseudonyms were used in transcripts and other identifying details were altered. Care was taken to ensure that any subsequent reports and publications would not identify individuals by name or inference.

2.6.4.4. Promoting trust in the research relationship

It is argued that an inevitable power imbalance exists within the research relationship, *"even when the researcher has an intellectual and emotional commitment to the people being studied"* (Hammersley & Atkinson 1993, p274). When the researcher has a health professional background, as in my own case, this power imbalance may be exaggerated (Etherington, 2001). First, the participant may feel obliged to participate out of a sense of duty or because they depend on the good will of those who care for them (Halloway & Wheeler, 1995). Second, although it is often assumed that a qualitative interview, which allows the participant to speak in their own terms, can be therapeutic (Small, 1998), this characteristic can potentially lead to exploitation and harm if participants are encouraged, through insensitive questioning, to divulge more information than they had anticipated. Therefore in order to promote trust and reduce the risk of participant exploitation and coercion I made clear my professional background as healthcare professional and researcher. I also made explicit that the research was not intended to be therapeutic or to be an adjunct to medical care. It was made clear both verbally and within the written information that potential participants should take time to consider whether they wished to participate in the study and a minimum of 24 hours consideration time was guaranteed. Further, I continually reassured participants that their involvement in the study was voluntary and that they were free to withdrawn at any time without it jeopardising their future medical care.

2.6.4.5. Reducing participant stress and anxiety

I am mindful that telling stories of illness and potential suffering may evoke anxiety and distress. Although it is difficult to predict the level to which each individual may exhibit these characteristics - as this inevitably depends on personal bibliography and individual experience – I undertook steps to reduce distress and anxiety.

I endeavoured to pose questions sensitively and participants were informed prior to and during the interview that they were at liberty to decline to answer any question that made them feel uneasy. The provision of support and information was made available to all study

participants. Interviewees were provided with an assurance that they would not be left in a state of distress. I always carried details of epilepsy support organisations in the form of leaflets and helpline telephone numbers, which I encouraged my participants to contact as necessary. Each participant was also offered the opportunity to speak with a clinical psychologist upon request and mechanisms were established to enable any participant requesting this level of support to be referred to a clinical psychologist at the participating NHS Hospital Trust.

It was explained to participants that should this situation arise they would be given the opportunity to reconsider their participation in the study and that I would accept their choice to withdraw should they wish to do so; emphasising once again that this choice would not affect their medical care. An assurance was also given that should a participant wish to withdraw then data collection would cease and any previously collected data, pertaining to them would not be analysed or reported.

Time was spent with each participant following the completion of their interview to enable them to reflect on our discussion and to establish whether they had any concerns with regard to the information they had disclosed. Although none of my participants expressed any misgivings, it was explained that any section of the interview causing them concern could be deleted if they so wished.

2.6.4.6. Strategies to avoid participant misrepresentation

The interpretive nature of qualitative research means that the published results are only one version of the truth (Richards & Schwartz, 2002). In the present study I accept that my role as researcher, my motives and reasons, and the interactional style that I brought to this endeavour will make an inevitable contribution to the findings that are offered to the reader. For these reasons the validity of the findings (discussed in greater detail in section 2.6.5) needs to be judged in relation to the care and transparency with which the data were collected and analysed. To this end I kept a reflexive journal throughout the study as a means of promoting an internal dialogue for analysing and understanding important issues throughout the research process (McLeod & Balamoutsou, 2000). I kept meticulous records of the interviews, which were audio taped and subsequently transcribed verbatim (Mays & Pope, 1995) and the process of analysis was documented in detail (Mays & Pope, 1995; Chiovitti, 2003). The findings were grounded in the data (Nijhof, 1998; Chiovitti, 2003) and participant validation was used as a further step towards the final interpretation by

providing each participant with an opportunity to comment upon the interpretation of their words and intentions (Mishler, 1986a).

2.6.4.7. Potential benefits to participants

Consideration was also given to the potential benefits of participating in this research study. Whilst the patient information sheet did not imply direct benefit to those participating, it did suggest that participants might appreciate being given the opportunity to tell their side of the story and that the findings from this study might benefit others in the longer term. Reflecting on my journal entries it is apparent that many participants actually wanted to spend time talking with me and many expressed interest in the fact they were able to give feedback and comment on their interview transcripts. For example, Karen commented how she *"enjoyed being involved"* and it was *"(…)certainly more interesting than numbers or just giving short responses to a lot of questions".*

2.6.5. Issues of authenticity in narrative inquiry

> *"Human science can no longer only seek mathematical and logical certainty. Instead, it should also aim at producing results that are believable and verisimilar".* (Jerome Bruner, 1986, p11).

Over the past few decades an extensive dialogue concerning the value or quality of qualitative research has occurred, which has resulted in alternative ways of determining the quality of knowledge generated within the interpretive paradigm (Bailey, 1996). Within this literature, it is proposed that research findings should be evaluated for trustworthiness, credibility, authenticity, and / or goodness (Bailey 1996). My own position is that a study of this nature is credible when it presents faithful descriptions and can show how interpretations have been arrived at. I therefore draw guidance from Lieblich and colleagues (1998) and from Riessman (1993); each offer a set of four criteria, outlined in Figure 4, which I attempted to address during the conduct of this study in order to demonstrate the 'credibility' of my own work and on which subsequent quality judgments could be based.

Figure 4: Approach to ensuring validation in narrative work

Lieblich et al (1998, p173)	**Riessman** (1993,p65-68)
Width: This refers to the comprehensiveness of evidence that is provided to enable the reader to make an informed judgement on the evidence and its interpretation	***Persuasiveness****:* This is similar conceptually to Lieblich's criterion of width but also includes elements of plausibility and style
C*oherence**:* As it applies to the way different parts of the interpretation create a complete and meaningful picture. For example, internal coherence - how the parts fit together; and, external coherence - how the research compares to existing theories and previous research	***Coherence:*** This is the means by which the narrative researcher demonstrates that an interpretation is more than ad hoc and is used to gain differing perspectives on the story
Insightfulness: This refers to the sense of innovation or originality in the presentation of the story and its analysis, for example does this research facilitate greater insight into the reader's own life?	***Correspondence*****:** This relates to the process of taking the analysis back to those studied for verification and/or discussion
Parsimony: This refers to the literary merits of oral or written presentation of the story. Namely, the ability to provide an analysis based on a small number of concepts, which is elegant or has aesthetic appeal	***Pragmatic Use****:* This refers to the extent that a study will become the basis for further research by other investigators and in contrast to other validation criteria is future orientated

Part of the process of validation within this study involved the use of other readers including my academic supervisors, fellow researchers and participants, to judge the authenticity and trustworthiness of my work. By involving other readers whenever possible - sometimes only to provide an alternative reading of a specific text, at other times to engage in shared analysis of material - my intention was to make the research process visible and enable systematic scrutiny (Polkinghorne, 1988; Mishler, 1990; Riessman, 1993; Sandleowski, 1993). Mishler (1990) tells us that credible and valuable narrative interpretation presents:

> *"data in the form of the text used in the analysis, with full transcripts and tapes that can be made available to other researchers;…methods that transformed the texts into findings; and…the direct linkages shown between data, findings and interpretation".* (Mishler, 1990, p429).

By presenting my own data in this manner I sought to enhance the authenticity of the findings, not privileging my own position as researcher and sole interpreter. However, it is important to emphasise that within narrative analysis, the involvement of other readers is not driven by a wish to achieve consensus or convergence in interpretation (McLeod & Balamoutsou, 2000), for there is not necessarily just one correct interpretation of the structures, meanings or context of narratives, neither is there a specific set of rules that if followed confer credibility. Rather:

> *"trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and therefore auditable: it is less a matter of claiming to be right than to have practiced good science".* (Sandelowski, 1993, p2).

Polkinghorne (1998) emphasises the reflexivity employed by the narrative researcher in the process of building a reasonable and believable report by, "*configuring the events in such a way that their parts in the whole story become clear"* (p171). Also, Sandelowski, (1993) considers that the *revisionist nature* of narratives – research participants often change their stories from one telling to the next – invalidates the notion that a valid work is a conventionally reliable one (Sandelowski, 1993, p4). It seems logical then, from these perspectives, that a reasonable and believable account is a valid account by ordinary definition, assuming that it is:

> *"Well-grounded or justifiable; being at once relevant and meaningful; appropriate to the end in view; having such force as to compel acceptance".* (Merriam-Webster, 2007).

The term 'valid' does not have to pass the test of limited definition within formal science, a definition that would restrict validity to the paradigmatic stream of inquiry.

CHAPTER THREE

3. Constructing epilepsy: the importance of time, place and context.

3.1. Introduction

What is epilepsy? An answer to this question defies simplicity. Early accounts of the condition - originating most likely from the middle of the first millennium BC, serve to establish a continuing tension between medical and mythical conceptions of epilepsy (Tempkin, 1971). That epilepsy is not just a clinical condition, but also a social label (Arnston et al.,1986) means even today the biologic and psychosocial aspects of the what is epilepsy question are likely to elicit different responses from those who treat epilepsy and those who live with epilepsy.

My aim within this chapter is to outline the various discourses that surround the phenomenon of epilepsy. Each of these discourses represents or 'constructs' the condition in a different way. Parker (1992) provides a working definition of a discourse as, *"a system of statements which constructs an object"* (p5). This system of statements (including meaning, metaphors, representations, images and stories) together produce a particular version of events; paint a particular picture; and, provide a particular way of presenting the object to the world. In this instance, each discourse claims to say what epilepsy really is, that is, makes a claim to the truth. In presenting this discussion, my purpose is not to stand in judgment of what has gone before or of what is upheld today. Rather, I have done so simply because it creates a useful platform upon which to illustrate the ways in which the phenomenon of epilepsy has been understood.

Following the notions of Foucault (1973b; 1974), knowledge and truth should not be considered essential and ahistorical. In the Foucaldian paradigm, the notion of what people can know is always limited by their contexts; hence, that which constitutes truth and rationality is not inevitable and changes across time and place. Throughout this discussion, I will attempt to show how each discourse brings different aspects of the epilepsy phenomenon into play, raises different issues for consideration and carries different implications for action.

3.2. Epilepsy as a moral condition

Earliest descriptions of epilepsy can be traced back to Babylonian times (Wilson & Reynolds, 1990), wherein epilepsy is constructed as the work of demons and ghosts:

> *"If epilepsy falls once upon a person or falls many times, it is the result of possession by a demon or a departed spirit"* (Wilson & Reynolds, 1990, p189).

Reynolds (1990), notes that the Babylonian texts were describing exactly the same condition that we see today. They provide accurate accounts of seizure types recognised in modern epileptology including, for example, tonic–clonic, absence, complex partial, Jacksonian, or even gelastic seizures. Although the knowledge portrayed in these clinical surveillances lacks understanding of pathology or of brain function, they nevertheless, according to Reynolds, mark a milestone in the history of epilepsy.

Different types of observed seizure manifestations were causally attributed to different demons. In doing so, the Babylonians established an ancient 'labelling system' by which to identify different epilepsy symptoms; including, for example, "seizure by a ghost" and "hand of a ghost", which are believed to be the ancient terms for nocturnal epilepsy (p187). Thus, every attack, irrespective of its type or frequency was considered to be epilepsy; its manifestation a result of possession. Here for example, Reynolds (2009) identifies an account of a left-sided focal motor attack, in which progression to loss of consciousness makes it harder to drive out the demon:

> *"If at the time of his possession, while he is sitting down, his left eye moves to the side, a lip puckers, saliva flows from his mouth, and his hand, leg and trunk on the left side jerk like a newly slaughtered sheep, it is miqtu. If at the time of the possession his mind is consciously aware, the demon can be driven out; if at the time of possession his mind is not so aware, the demon cannot be driven out"* (Reynolds, 2009, p338).

Scriptural accounts of "*falling down with eyes open"* and "*fits of rage"* (Daras et al., 2008), as well as the prevention of persons "*possessed by a malevolent power"* from entering the temple - noted in the ancient Egyptian text of Esra (Rows & Bond, 1926), have all been interpreted as referring to epileptic seizures. The word epilepsy comes from the Greek verb *epilamvanein* – 'to be seized', 'to be taken hold of' or 'to be attacked'. Similarly, the Hebrew word for epilepsy, *nichpeh*, implies an individual being 'seized' upon by a demon. These ancient observations of seizures were underpinned by theories of evil or punishment enacted upon a person by god. There are also writings in the New Testament which align

epilepsy to madness; and the misconception that a person with epilepsy was a 'lunatic' remained common throughout mediaeval times.

In contrast, epilepsy was considered to be 'the sacred disease' by the ancient Greeks; a sign of honour given by the gods. In Greek and Roman worlds the word 'lunatic' (because of its assumed link to the cycles of the moon) was limited to epilepsy and was distinguished from 'maniacs' or mad people who were possessed by demons, not gods (Hill, 1981). Such popular, common misconceptions and superstitions were only brought into question when Hippocrates challenged these believers to justify their labelling of epilepsy as 'sacred'. The Hippocratic text *On The Sacred Disease* was the first monograph on a single disease and records the tension between *"scientific"* and *"magic"* interpretations of epilepsy (Tempkin, 1971). Hippocrates asserted that epilepsy is no more divine than other diseases and in so doing presented a counter-argument: "*the fact…that the cause of this affection* [epilepsy]…*is in the brain"* (Hippocrates, as translated by Jones, 1984). Hippocrates described the generalised epileptic seizure, recognised the hereditary nature of the condition and noted its more frequent appearance in children; in so doing Hippocrates argued epilepsy properly belonged not within the domain of religion or magic but within the domain of medical investigation. Positioning epilepsy medically, Hippocrates noted treatment for this condition must be by diet and drugs, not religious incantations (Temkin, 1971**;** Engel & Pedley, 2008).

Andermann (1995) suggests that boundaries between magic and science were not always so clearly delineated. In this regard she cites Lloyd (1990) who proposes that rather than creating a confrontation between science and magic, the Hippocratic approach may just be another alternative form of magic; one competing for recognition among other forms of healing available at that time. Andermann goes on to suggest that if (as Lloyd argues), magic is used in response to situations beyond the technological resource of a society, perhaps the temple medicine popular in the time of Hippocrates was a reasonable option. Lloyd offers the following critical reflection:

> *"Where, as with epilepsy, some kind of psychological support was the most that could be hoped for, then everything would depend on the prevailing attitudes of those to whom that support was being offered. The Hippocratic approach might suit one type of clientele. But the temple healers, for their part, and the purifiers, for theirs, might argue that their treatments drew on a more deeply rooted set of traditions and assumptions and so would be more helpful, where most ancient Greeks were concerned, than the Hippocratic brand of rationalism".* (Andermann, 1995, p53).

In consideration of the anatomical and physiological knowledge of the Hippocrates, Lloyd views this not so much as a shift from magic towards science, rather as a difference in style of thinking. The significance of the Hippocratic writings however, was the separation made between natural and magical forms of knowledge for the first time in Western literature.

While 'moral' explanatory theories about the causes of epilepsy continue to permeate lay beliefs about the condition in developing societies, public attitude surveys suggest that such beliefs are no longer generally held in the West. Nevertheless, my justification for paying attention to such beliefs within this discussion is two-fold. First, the relationship between these images of epilepsy and a present-day individual's self-identity may be difficult to judge. Second, the discussion highlights the diversity and variation in beliefs about epilepsy; and in so doing serves to demonstrate the need for researchers and practitioners to consider the social context, or to use Kleinman's (1995) term, the *local worlds* (p1321) in which people with epilepsy engage in everyday activity and experience their condition.

Although the focus of this review is on experience of people with epilepsy in the developed world, epilepsy has raised a lot of attention (among a variety of disciplines) as a complex set of cultural concerns. For example, in developing countries, where indigenous cultural beliefs about seizures remain common, there is a wide range of ideas about causes of epilepsy (Conrad, 1992). Andermann (1995) suggests that theories about the causes and subsequent treatment of epilepsy within developing countries can be accounted for within four major categories. The first category is that of biomedicine - epilepsy as a disease of the brain, first adopted by the Hippocrates (1984) - which I touched upon previously and to which I shall return later in this discussion. The other three are concerned with epilepsy as punishment for sin (Levy, et al., 1979), epilepsy as bewitchment or possession (Tekle-Haimanot et al., 1991; Reis, 2000) and epilepsy as contagion (Jilek, 1979; Awaritefe, 1989; Baskind & Birbeck, 2005). As a consequence of these beliefs, people with epilepsy have been variously socially outcast (Geil 1968; 1970; Shorvon, 1988); perceived by communities as belonging to a different category of persons (Nchoji et al., 1989). Such appellations have led to considerable problems for both the individual and their family members (JilekAall et al., 1997; Conrad, 1992; Birbeck, 2000a). Examination of the social and economic impact of epilepsy and the issue of stigma (Lai et al., 1990; Fong et al., 2002; Jacoby, et al., 2005a; 2008; Cuong et al., 2006; Birbeck et al., 2007) serve to reinforce the belief that societal

discrimination of those with epilepsy in developing regions carries a heavy burden of stigma (Shorvon, 1988; Whyte, 1991; Kleinman et al., 1995).

It is clear from this discussion that although cross-cultural beliefs about the source of epilepsy vary, they nevertheless illuminate the extent to which social forces contribute to the experiential effects of epilepsy. Definitions of a problem are influenced by the beliefs of others, be they individuals or groups about what constitutes 'truth' or 'fact' about that problem; some of those claims inevitably gain greater support by members of a society than others (Conrad & Schneider, 1992). The appellations of, for example, sin, demonic possession or illness indicate different ways of 'seeing' the phenomenon of epilepsy. As an example, attributing epilepsy to spiritual causes likely underpins health-seeking behaviour involving attendance at religious leaders or traditional medicine healers rather than Western medical doctors (Adamolekun et al., 1990; Feksi et al., 1991; Andermann, 1995). In addition the shame and fear associated with epilepsy often deters those affected from accessing appropriate treatment. It is argued that such cultural interpretations and behaviours form major contributors to a developing-world 'treatment gap' - the proportion of people with active epilepsy who are untreated is estimated as between 70-90% (GCAE, 2004). And this gap in treatment has inevitable consequences for education, employment and socialisation (Jallon, 1997; Scambler & Hopkins, 1986; Birbeck, 2000b).

As a means to addressing the social realities of epilepsy, the Global Campaign Against Epilepsy (GCAE) seeks to reduce the treatment gap and bring epilepsy 'out of the shadows' (GCAE, 2003). Yet, even in developed countries where access to appropriate treatment is less problematic, the illusive causal nature of epilepsy (Schachter, 2003) fuels the potential for continued misattribution (Spatt et al., 2005). For example, Austin et al., (2002) note that 22% of American adolescents reported being uncertain about as to whether epilepsy was a contagious condition. Western misunderstanding about epilepsy has also been shown to evoke adverse reactions in areas such as education (Gallhoffer, 1984), employment (Ratsepp et al., 2000), insurance (Thorbecke, 1997; Jacoby & Jacoby, 2004) and healthcare provision (Chadwick, 1990).

3.3. Biomedical constructions of epilepsy

Historically, advancement of medical understanding about epilepsy was slow, with biomedical explanations for epilepsy only beginning to emerge following the Enlightenment, with its search for objective, scientific truths (Temkin, 1971).. As the clinical

view of epilepsy began to take hold, society began to view those with epilepsy in a different - although arguably a no less socially stigmatising – light, as new prejudices against those with epilepsy began to replace old ones (Pasternak, 1981). New prejudices were based on the concept of epilepsy as neurosis; the cause of, or the result of various mental or emotional aberrations. During this time, scientific debate about what to include in the concept of epilepsy led to a number of treatises on 'convulsive diseases' which included hysteria, tetanus, tremors, rigours and other paroxysmal movement (Reynolds, 2009).

Because convulsions were not commonly associated with brain lesions, the frequent observations of those who were treating them in mental institutions lent weight to a theory of association between convulsions and mental or behavioural disorders until well into the 20th century (Reynolds & Trimble, 2009). For example Dr Joseph Price, writing in the *Journal of Nervous and Mental Diseases* in 1892, about the etiology of epileptic seizures, noted debauchery, chocolate, coffee, excessive lust, and amorous love songs were all *"abundantly proven and great factors in its causation"* (Price, 1892). Noteworthy here is the 'moral' ideas that underpinned the construction of epilepsy even though those ideas derived from a biomedical base. A train of thought existed that epilepsy, like hysteria, was the product of intense or repressed emotion. This line of reasoning was the empirical basis for connecting epilepsy to insanity, criminality, and to an impulse to commit violent acts and aggression (Gunn & Fenton, 1969; Rodin, 1973). Notions of sexual deviance; hereditary degeneracy in intellectual and moral function and in temperament, resulting eventually in dementia or idiocy; hyper-religiosity and hyper-sexuality all underpinned the construction of a specific 'epileptic personality' (Pasternak, 1981; Bear et al., 1984; Reynolds & Rodin, 2009). This theory of 'epileptic personality' was, according to Hill (1981), responsible for labelling the person with epilepsy as someone destined to be 'mad and bad'; capable at worst of murder but at least of moral depravity. Such prejudicial opinion of the 'epileptic personality' was common to asylum medicine and was prevalent in almost all mental health establishments of the time. As Berrios (1984) points out, the association of epilepsy with insanity persisted until early in the 20th century.

The fact that those with epilepsy had long been institutionalised in mental asylums came under public scrutiny and the reform movements of the early 19th century were, to some extent, beneficial in reducing the social suffering of people with epilepsy. There was interest from both lay and medical communities in establishing 'colonies' as a means of serving the social and medical needs of people with epilepsy. In Britain, The Charity

Organisations Committee Report *The Epileptic and Crippled Child and Adult* in 1893 is heralded as an historical landmark in social suffering (Daras et al., 2008) by clearly articulating the needs of people with epilepsy and the serious lack of resources available at that time to meet those needs. In 1909 the International League Against Epilepsy (ILAE) was established, marking a major initiative worldwide to organise professional interest in epilepsy as well as address scientific and social aspects.

However Eisenberg (2008) argues the conclusion of the medical profession that those with epilepsy would be 'best off' in isolated, out-of-sight communities was driven less by a philosophy of best care and treatment provision, rather by their frustration over the failure of treatment methods. This movement to hospitalise people with epilepsy could now be viewed - from a Foucaldian perspective - as a demonstration of 'modern' state's social control where medical knowledge is tied up with the regulation of sickness. Interestingly, one such institution in New York State opened in 1896 did not change its name: *Craig Colony for Epileptics,* until 1967 (Dwyer, 1992).

Around the mid-19th century, increasing scientific knowledge began to bring to light the underlying causes of epilepsy and clarify the relationship between emotions and epileptic seizures. These concepts were influential in shaping modern medical understanding of epilepsy and can be attributed to Robert Bentley Todd (1849) and to the various writings of John Hughlings Jackson (1931). Todd, through the development of an electrical theory of brain function, viewed seizures as the result of electrical discharges in the brain; and while Jackson's early writings were dominated by vascular theories of epilepsy (Temkin, 1971), he later established the idea of different categories of seizure, each with its own physiology and semiology. His recognition of focal motor seizures - known as Jacksonian seizures, not only established the responsible area of the brain but enhanced future understanding about cerebral control of voluntary movement.

Unfortunately, this early rationalisation of epilepsy did not eradicate the existing social prejudice against those with epilepsy and the long and ferocious interest framing epilepsy as a condition of inherited physical and moral degeneracy continued up until World War II. Although genetics was incompletely understood in the 1930's, in some cases seizures appeared to be familial. This resulted in 'epileptics' being considered an appropriate object of eugenic practice; castration and sterilisation were identified as potential treatments for epilepsy. In 1936, the American Neurological Association Committee for the Investigation of

Eugenical Sterilisation published a report (Myerson et al., 1936) indicating sterilisation should be voluntary, done only with patient consent, and under supervision of a trained board. The report indicated that in special or selective cases, sterilisation might be indicated in epilepsy - but that for epileptics with infrequent seizures and an 'intact personality', sterilisation should not be performed (Cereghino, 2009). However, reports in the United States of involuntary sterilisation, and an immigration policy which prevented persons with epilepsy from entering the United States, are noted by Dwyer (1992), who also claims in her *Stories of Epilepsy*, that physicians, frustrated by the failure of medical therapy, were attracted to eugenics as a social means to manage the condition. Lennox (1960) highlights the irrationality of eugenic and immigration laws which discriminated against epilepsy on the grounds that it was an hereditary disease, when available evidence indicated the genetic basis of epilepsy was in fact weaker than that of other diseases. This medical prejudice towards people with epilepsy certainly appears disproportionate to the evidence available. In reviewing medical progress in epilepsy in 20th century psychiatry, Szasz (1966), cited by Bagley (1972), makes the following observation:

> *"In the initial decades of this century much was learned about epilepsy. As a result, physicians gained better control of the epileptic process (which sometimes results in seizures). The desire to control the disease however, seems to go hand-in-hand with the desire to control the diseased person. Thus, epileptics were both helped and harmed: they benefited in so far as their illness was more accurately diagnosed and better treated; they were injured in so far as they, as persons, were stigmatized and socially segregated. Was the placement of epileptics in 'colonies' in their best interest; or their exclusion from jobs, from driving automobiles, and from entering the United States as immigrants? It has taken decades of work, much of it incomplete, to undo some of the oppressive social effects of 'medical progress' in epilepsy, and to restore the epileptic to the social status he enjoyed before his disease became so well understood". (*Bagley, 1972, *p36).*

We can trace attempts to dispel the confusion surrounding the nature of some paroxysmal behavioural, psychological and psychotic disorders associated with epilepsy back to Todd (1809-1860) and the concept of neural discharges. However, modern electromagnetic theories of epilepsy only gained wide acceptance following Berger's (1929) report of human brain waves which could be recorded using electrodes placed on the scalp. Following World War II Henri Gastaut began his electroencephalography (EEG) recordings and was able to show abnormal electrical signals prior to seizure onset Gastaut, recognising the important relationship between the EEG and clinical seizure semiology, and the need for a common mode of communication, became the driving force in the effort for classifications and a dictionary of epilepsy (Gastaut, 1973). The development of clinical EEG and the later

introduction of video telemetry in the 1970's and 1980's provided a reasonably sound clinical basis for identifying and separating epileptic seizures from non-epileptic attacks (Reynolds & Trimble, 2009).

Biomedically, in the 21st century epilepsy is no longer considered a specific disease, or even a single syndrome, but rather categories of a broad range of symptoms arising from an array of disordered brain functions which in themselves may be secondary to a number of pathogenic processes (Englel & Pedley, 2008). Current classificatory work defines that there may be as many as 40 different types of epilepsy (JEC, 2011), consisting of at least 29 syndromes and a further 12 or so clinically distinct groups defined by the specific cause or underlying cause (Sanders, 2004). At least 40 different types of seizure associated with epilepsy have been described; some patients experiencing more than one type in their lifetimes (JEC, 2011). Current figures suggest that approximately 60% of people with epilepsy have tonic-clonic seizures, 20% complex partial, 12% mixed tonic-clonic and partial, 3% simple partial and less than 5% absence seizures, myoclonic seizures and other types (NICE, 2012). Around 3% of people with epilepsy are photosensitive and have seizures induced by photic stimuli (Betts et al., 1998). Thus, epileptic seizures, while often socially stereotyped as visual and dramatic (Harrison & West, 1977; Jacoby et al., 2004), in reality vary in nature between individuals and are classified on a presumed dichotomy between where in the brain they arise: 'partial' (focal, local), where only a part of the brain is affected and which depending on their type, may or may not impair consciousness; or 'generalised' (ILAE, 1981), where the entire brain is affected and as a result all normal functions of the cortex to be temporarily suspended (Schachter, 2003).

Most recently, the International League Against Epilepsy (Fisher et al., 2014) Classification of Epilepsies and Epileptic Syndromes has characterised a variety of conditions or *epilepsies* not just by seizure type but also by other characteristic clinical markers such as: etiology, presence or absence of hereditary factors, age of onset, seizure frequency/severity, EEG findings and prognosis. As in previous classifications, epilepsy is divided into two broad categories: 'idiopathic' and 'symptomatic'. In the former, genetic factors are important and epilepsy onset is usually age related; the condition tends to be self-limiting and to respond to anti-epileptic drug treatment. Symptomatic epilepsies are defined those in which seizures are the consequence of an identifiable lesion or other physical or metabolic cause.

One claim that the present-day Western biomedical model supports is that anyone can be affected by seizures. Epilepsy has been shown to occur in both men and women; it can begin at any age, though most frequently diagnosed in infancy, childhood, adolescence and old age. Recent epidemiological studies show that one in every ten people will have at least one epileptic seizure during their life; a third of whom will develop epilepsy. Thus, epilepsy is reported as one of the most common disorders of the brain, affecting some 50 million people worldwide (WHO, 2012), an estimated 600,000 of who reside in the United Kingdom (JEC, 2001)

The introduction of Phenobarbitone in 1912 marks a turning point in the medical treatment of epilepsy (Reynolds, 2009). Empirical evidence continues to demonstrate that for the majority of patients with epilepsy, anti-epileptic drug treatment is successful (Shorvon & Reynolds, 1982; Elwes et al., 1984; Placencia et al., 1994). With effective management up to 70% of people with active epilepsy have the potential to become seizure free (Sander, 2004) and for those entering remission, drug treatment can subsequently be withdrawn (Berg & Shinnar, 1991; MRC, 1991). For these reasons epilepsy is now viewed in medical terms as a relatively benign disorder with an excellent clinical outcome (Sander & Sillanpaa, 1997). This more optimistic view of prognosis for the majority of patients with epilepsy reflects the change in medical understanding. As recently as 1968 Rodin (cited by Reynolds, 1990) reported that four-fifths of all patients with epilepsy are likely to progress to a chronic seizure disorder; reinforcing the earlier view (Gowers, 1881) that *"the spontaneous cessation of the disease was an event too rare to be reasonably expected".* Yet current population-based data indicate that no more than 20-30% of newly diagnosed patients will develop chronic epilepsy. For example, the National General Practice Study of Epilepsy (1995), conducted throughout the United Kingdom between 1984 and 1987, showed 3 year and 5 year remission rates of 87% and 71% respectively for idiopathic epilepsy. In a more recent review of the effect of 265 drug changes in 155 people with chronic epilepsy, 16% were rendered seizure-free after the introduction of one drug, with a further 21% gaining a considerable reduction in seizure frequency. Overall, 28% of the cohort was rendered seizure-free by one or more changes to their drug treatment (Luciano & Shorvon, 2007).

However, we need to remain mindful that for the 20-30% of patients whose seizures prove non-responsive to anti-epileptic drug treatment a somewhat less benign clinical and social picture emerges. Those with intractable seizures appear predisposed to an increased risk of psychiatric co-morbidity (Lambert & David, 2000) and a reduced quality of life (Jacoby &

Baker, 2000). Intractability is more apparent in particular epilepsy syndromes (Geithner, 2012); for particular etiologies; and for particular seizures types (Aicardi & Shorvon, 1997; Fisher et al., 2014). Although advancement in anti-epileptic drug therapy has facilitated seizure control there are no therapies free of side effects - 88% of patients with epilepsy, in a recent European survey reported at least one anticonvulsant related side effect (Baker et al., 1997) - and that there is no cure for epilepsy remains a 21st century reality.

An increasingly important contribution to present day treatment, and a potential cure of refractory epilepsy, is that of surgical resection of the brain (Schmidt & Loscher, 2003; Spencer & Huh, 2008; Rugg-Gunn & Sander*, 2012*). However, surgical intervention for seizure relief is by no means a new technique – it dates back to antiquity; nor is it a technique that was originally confined to the brain (Daras et al., 2008). Extreme interventions such as, for example, surgical removal of peripheral lesions considered to be seizure triggers (Cooke, 1823); surgery on both male and female genitalia (the consequence of the perceived equivalence of genital irritation, orgasm and seizures; Duffy, 1983; Black 1997), and castration (Bacon, 1880) were all reported interventions for the so-called 'prevention' of seizures. However, it was Jackson's (1888) major advance of discovering both the site selection and the effectiveness of temporal resective surgery that lead to the first suggestion of a potential cure for epilepsy. In 1934 a task force was established to investigate aspects of preoperative diagnosis, identification and localisation of the epileptic focus at the Montreal Neurological Institute. This work was developed, following World War II, with further management programs for both the medical and social care of those with epilepsy and as such constituted a major advance in the overall treatment of epilepsy (Daras et al., 2008).

Despite the major changes in the Western biomedical view of epilepsy and seizures, and in the way it is managed medically, people with epilepsy are still faced with not only learning to deal with the physical impact of seizures, but also learning to cope with the associated, harmful social and psychosocial consequences, which are not directly related to the actual disease process (Engel, 2000). The limitations imposed by statute, prejudice, fear and lack of understanding have major implications for social functioning and life choices. Not surprisingly these challenges are easier for some individuals to cope with than others (Baker & Jacoby, 2000). Epilepsy may have been claimed as 'sickness', but competing moral explanations still appear to influence ideas and perceptions of epilepsy and position it still as a source of stigma.

3.4. Epilepsy as stigmatising illness

> *"To have epilepsy is to open oneself up to the full force of past and contemporary social prejudice and misunderstanding".* (Trostle, 1997, p2187).

According to Weiss and Ramakrishna (2001) health-related stigma is a medically unwarranted, adverse judgment of a person; and certainly there is a plethora of research to support the view that the social prognosis of epilepsy is likely less benign than the clinical one. This appears to be the case particularly for those people with epilepsy who live in the developing world (WHO, 2009) and for those with refractory epilepsy (Jacoby & Baker, 2000). Temkin's (1971) analysis of the social representation of epilepsy historically aptly demonstrates how both medical and mythical conceptions of the condition have positioned epilepsy as a discredited disorder through time and place. Although mythical and demonic explanations of epilepsy have tended to give way to biomedical ones (Jacoby et al., 2005b), the discussion thus far demonstrates that physicians too have been guilty of prejudice towards people with epilepsy, attributing negative and anti-social traits to those suffering with the condition when their rules of objective intellectual enquiry ought to have guarded them from doing so. Thus, despite the 'medicalisation' of epilepsy and the relative success of clinical treatment regimes, this legacy of misconception continues to shape present day attitudes and beliefs about epilepsy worldwide (McLin & de Boer, 1995; Jacoby et al., 2005b).

Dell's (1986) observation that the stigma of epilepsy remains 'real and serious', presenting a threat to the quality of life of those affected by it, is supported by the application of both formal and informal sanctions evident in society today. For example, despite the fact that in many countries those suffering with epilepsy have a 'prescribed disability' and hence an entitlement to protection under the law, the limitations imposed by statute, prejudice, fear and lack of understanding sometimes function outside a framework of supportive evidence. While stigma and discrimination may not be inevitable for people with epilepsy, their negative effect on the social identity of affected individuals has the potential to impede psychological well-being, social functioning and life choices (Jacoby, 2002).

I shall return to the attitudes of others and the perceived impact of stigma on the quality of life of those suffering from epilepsy later, but first, by way of background, I consider what stigma theory tells us about the nature of stigma for the person with epilepsy and how this compares with illness-related stigma in general.

3.4.1. Goffman on stigma

The term 'stigma' originated in ancient Greece and referred to a sign, or mark cut, or burned into the body, designating the bearer as a person who was morally defective and should be avoided (Weiner et al., 1988). In the 20th century the meaning of stigma was extended by sociologist Erving Goffman to refer to an attribute of a person that is 'deeply discrediting', and reduces him or her 'in our minds from a whole and usual person to a tainted, discounted one' (Goffman, 1963).

In his study *Stigma* (1963), Goffman examines the problems of identity for individuals whose *virtual* social identity (what they ought to be) does not match their *actual* social identity (what they actually are). People who experience a gap between these two identities are, in Goffman's terms, stigmatised. Stigma, then, according to both Goffman and to his sociological peer, Becker (1963), is a social response, derived from a societal view of what constitutes differentness or deviance and the subsequent application of rules and sanctions against the person ascribed that difference. Goffman further asserts that even though a stigmatised person may strive to free themselves of this 'contaminated' identity – in the case of epilepsy by seeking treatment to control seizures – they cannot regain 'normal' status, only the status of one who was 'once contaminated'. Yet the concept of 'once contaminated' may bear little relevance for people with epilepsy since, if the condition is not curable, only controllable, the threat of a 'contaminated' identity remains ever present.

According to Goffman's (1963) analysis of the social psychological implications of stigma an important aspect of a stigmatising condition relates to its visibility to others: and so whether the individual concerned is immediately 'discredited' or potentially 'discreditable'. He argues that the problems faced by a discredited individual (i.e. those with a visible stigma) are different from those faced by the discreditable individual (whose stigma is hidden). For example, in the former, the central issue faced by the individual is the ability to manage the tension that may be created by the negative impressions held about them by 'non stigmatised' persons with whom they interact. For the discreditable individual however, who is able to choose to conceal their condition or 'pass' as Goffman describes it, the central problem becomes one of management of information rather than tension. In this situation the individual, having chosen not to reveal their condition, must continually monitor the information they exchange to avoid inadvertently disclosing their failing. The

applicability of Goffman's theorising to epilepsy is evident in relation to the coping and adaption mechanisms used by those affected by the condition. For example, many participants in a study conducted by Scambler (1989), acknowledging their newly acquired epileptic identity as undesired difference, and as such potentially stigmatising, chose concealment as their first-choice coping strategy. The perceived need by those with epilepsy to keep their condition a secret was also highlighted by Schneider and Conrad (1981) who identified concealment as a key strategy of adaption. The day to day management of concealment was found to be complex, with the degree of secrecy reflecting the individual's perception of stigma. A similar finding was evident in a cohort of adolescents with epilepsy. Here over 50% reported keeping their condition a secret and 70% stated they never or rarely spoke about it. Paradoxically, despite these admissions, the majority of participants denied any significant effect of their epilepsy in respect of their relationships with peers (Westbrook et al., 1992).

Goffman's (1963) account seems to firmly place the burden of stigma with the sufferer, and responsibility with the stigmatised individual to accept their 'spoiled identity' and attempt to be 'normal' in order to assist the non-stigmatised. However, I would argue that by focusing on the stigmatised and placing emphasis on the management of the 'spoiled identity', Goffman's work dilutes the arguments that focus on making society change, thus, potentially perpetuating the existence of discrimination and disadvantage. Anspach (1979) argues that Goffman's perspective also fails to recognise the role of agency, where through for example, political activism, so-called deviant individuals carve out an identity for themselves which they broadcast to the so-called 'normals' of society.

3.4.2. Components of stigma

Link and Phelan (2001) argue that stigma exists only when a number of interrelated components converge. First, human differences must be considered as socially relevant; secondly, these differences must be linked to negative stereotypes; thirdly, such stereotypes must in turn lead to social distancing and separation, and fourthly, this situation leads subsequently to status loss and discrimination. The fifth component is that of power, which Link and Phelan consider critical in the social production of stigma. Only those groups possessing power – social, political or economic – can impose their views about a particular condition as stigmatising. The possession of power can be expected to vary with specific cultures, location within history and societal structure (Burr, 1995). In

contemporary western society it is commonplace for doctors, science and medicine to be afforded a significant degree of power. Considering the theoretical fit of these components of stigma to epilepsy, we can trace the social relevance of epilepsy as 'difference' back to antiquity (Tempkin, 1971); and, link negative stereotyping to the unwarranted attribution of an 'epileptic personality' (Pasternak, 1981; Bear et al., 1984; Reynolds & Rodin, 2009) and to public attitude reports (see for example Harrison & West, 1977; Scambler, 1989) in which people with epilepsy were characterised as aggressive or potentially violent, retarded or slow, weak, antisocial and physically unattractive. The influence of power is demonstrated through the legal and statutory discriminations imposed on those affected by epilepsy – in the modern clinical picture epilepsy if no longer defined as 'possession' (i.e. badness), is still defined as 'sickness' and therefore as a form of deviance and stigma (Conrad & Schneider, 1992).

3.4.3. Dimensions of stigma

Developing earlier analyses of the contextual and dynamic nature of stigma, Jones and colleagues (1984), propose a framework which identifies a set of six dimensions along which stigmatising conditions differ. The first dimension, concealability, refers to whether a stigmatising condition must become obvious or whether it can be hidden from others. The authors described this as a critically important dimension of stigma since visibility plays an important role in producing negative social reactions. The second dimension is 'the course of the mark', and refers to the way the condition changes over time and its ultimate outcome. Thirdly, there is the dimension of disruptiveness, explained as the degree of strain and difficulty that the stigma adds to interpersonal relationships. The fourth dimension is aesthetic qualities – namely, how much the attribute makes the character repellant or upsetting to others. Origin, the fifth dimension, refers to how and who was responsible for the acquired stigmatising condition; and the sixth dimension, peril, focuses on the dangers associated with stigmatised persons, both real and symbolic.

The authors recognise that, these dimensions are neither exhaustive nor mutually independent. In their analysis of how stigma affects social relationships, disruptiveness is the crucial dimension of stigma. The conceptualisation of disruptiveness however, overlaps in many ways with other dimensions, thus each of the dimensions will have implications for how the stigma disturbs social interaction. In relation to epilepsy, seizures as a manifestation of the condition may be difficult to conceal - their degree of visibility will be

dependant on seizure type and severity, and on their responsiveness to anti-epileptic drug treatment. The dimensions of disruption and peril are represented by the sudden and unpredictable nature of seizures; they are socially disruptive and often viewed by 'onlookers' as frightening. Bagley (1972) suggests that by losing control people with epilepsy are seen as 'reverting to the primitive' and as such represent 'anomic terror' to those without seizures. Seizures are seen as 'uniquely dangerous' (Throstle, 1997) as they represent human weakness and unpredictability and consequently result in an affront to societal values (Ablon, 2002).

According to Crocker and colleagues (1998), visibility and controllability are the most important dimensions of stigma and research in epilepsy certainly appears to reflect this position. Community studies conducted in the United Kingdom (Jacoby et al., 1996) and across Europe (Baker et al., 1997) indicated that individuals with frequent, less well controlled seizures risked higher levels of perceived stigma than did those in whom seizures were either less frequent or in remission. A more recent study conducted by Aldenkamp and colleagues (2003) supports this view and suggests that people with well-controlled epilepsy do not show worrying reactions to the epilepsy and that their social prognosis is excellent, indicating that stigma seems to be associated with seizure frequency.

3.4.4. 'Felt' versus 'enacted' stigma

In addressing the concept of stigma in epilepsy, Scambler and Hopkins (1986), and subsequently, Jacoby (1994) sub-divide the consequences of the negative effects of stigma as being the result of 'enacted' or 'felt' stigma. The former refers to episodes of discrimination against people with epilepsy solely on the grounds of their social unacceptability, whilst the latter refers to the shame associated with being a person with epilepsy and the subsequent fear of enacted stigma. In the aforementioned community study, Scambler and Hopkins explored the reactions, experiences, and coping strategies of people with epilepsy, proposing a 'hidden distress' model. The model suggests that following diagnosis adults with epilepsy generate an acute sense of felt stigma before any exposure to enacted stigma. Secondly, the authors argue that felt stigma can be a 'self-fulfilling prophecy' whereby individuals who feel stigmatised by their condition attempt to conceal it when possible in order to protect themselves from active discrimination. In doing so, they prevent themselves from knowing whether their belief of discrimination would actually be realised. Thus, the diagnosis of epilepsy is generally only known within

close family circles, with only a few trusted individuals outside the family being informed, and with the number of informed individuals being related to seizure frequency. Thirdly, it follows that because perceptions of 'felt' stigma have an inevitable impact on the number of informed persons within an individuals' social network, this acts as a mechanism for reducing opportunities for 'enacted' stigma. Consequently, 'felt' stigma is far more prevalent than 'enacted' stigma and as Scambler (1989), notes, as a function of successful concealment, felt stigma typically proves more disruptive to the lives of individuals than enacted stigma.

Jacoby's (1994) study of people with epilepsy in remission supports the views of Scambler and Hopkins. She found that one third of respondents believed having epilepsy made it more difficult for them to get a job than those without epilepsy. Many respondents had not disclosed their condition to their employer, citing fear of discrimination as the reason for their concealment. That said, only 3% of those unemployed at the time gave epilepsy as the reason for unemployment; only 2% recounted any occasion of unfair treatment; and, only 3% cited discrimination as the reason for failing to get a job.

The hidden distress model has been challenged by other authors, on the grounds that it suggests people with epilepsy are responsible for their lower life achievement and implies that fear of disclosure is reasonable only if it follows particular incidents of discrimination (Trostle, 1997). More importantly, however, the focus on enacted stigma limits discrimination to specific acts or occurrences of verbal discrimination, which in isolation may bear little relevance to individuals' day-to-day manifestations of difference in terms of, for instance, not being able to drive or continually needing to take medication.

3.4.5. Operational levels of Stigma

Muhlbauer (2002) argues that illness stigma needs to be viewed at three different levels when considering the social reality of a condition. These levels are defined as *internalised stigma* – that which is felt from within the person with the condition, and is a reflection of their thoughts, beliefs, feelings and fears about being different; *interpersonal stigma* – that which occurs in interaction with others both within and without family networks, and during which the person with the condition is treated differently and negatively as a consequence of their health condition. Lastly, at the level of *institutionalised stigma* – that which reflects indirect expressions of different treatment of individuals with a condition as a group in larger society. While Muhlbauer's observations were made in the context of

mental illness, in considering each of these stigma levels in turn, their applicability to epilepsy is no less apparent (Guo et al., 2012).

3.4.5.1. Internalised stigma

Although it is difficult to quantify the degree to which people with epilepsy experience internalised stigma as such judgments depend on prior expectations, a study about patient perceived stigma involving over 5,000 respondents across 15 European countries, reported 51% of people with epilepsy feeling stigmatised, with 18% feeling highly stigmatised (Baker et al., 1999). Felt stigma has been found to affect men and women equally, although younger people are more likely to report feeling stigmatised than are older people (Westbrook et al., 1992; Jacoby et al., 1996; Ridsdale et al., 1996; Dilorio et al., 2003). Internalised or felt stigma in epilepsy has been identified by Jacoby (2002) as having a direct relationship with seizure frequency and illness trajectory. Felt stigma is positively associated with learned helplessness, depression, anxiety, impaired physical health status, increased somatic symptoms and other health problems, reduced self-esteem and reduced life satisfaction. Perceived stigma as a predictor of quality of life has also been identified; accounting for more of the variance in quality of life scores than clinical variables (Suurmeijer et al, 2000).

Ryan and colleagues (1980), argue that individuals with epilepsy do not feel universally stigmatised in all life domains, but differ in their experiences of how society reacts to their disease. In contrast, Amir and colleagues (1999), note the 'halo effect' of the subjective experience of a person with epilepsy, emphasising that epilepsy is so invasive to the life of the individual that its influence is felt in all life domains. Two implications are evident from these sets of findings. Firstly, it is apparent that medical management of the disorder alone is not always sufficient to control its social consequences. Secondly, and more fundamentally, if stigma is not all-pervasive, then unwarranted preoccupation with it may promote self-fulfilling expectations of discrimination among those with epilepsy.

3.4.5.2. Interpersonal aspects of stigma

The interpersonal aspects are played out in the negative attitudes held by others and their treatment of people with epilepsy. Bagley (1972) theorises that the prejudice expressed against people with epilepsy may be explained by 'fear' of apparently uncontrolled impulses suddenly manifesting themselves and the belief that people with epilepsy are morally

responsible for their sudden and fearful attacks. This expressed prejudice has also been recognised by Trostle (1997), who argues that the physical manifestations of epilepsy create a host of emotional and social reactions, which are then incorporated into lay beliefs and attitudes about the disease, as well as behavioral and legislative reactions to it.

An early study conducted by Harrison and West (1977) to investigate public attitudes towards epilepsy, found the public image of epilepsy consisted primarily of the 'grand mal' seizure. The investigators concluded that people tend to associate the outward manifestations of only the 'grand mal' (for example; falling, foaming, rigidity, shaking, loss of bowel/bladder control, cyanosis) with their vision of epilepsy and suggest this is due to the fact that the public only tends to observe the 'worst' end of the spectrum - those with less incapacitating forms of epilepsy tending to pass unnoticed in the general population. Overall, 50% of respondents reported having a negative experience in relating to a person with epilepsy.

Studies conducted worldwide, however, indicate improvements in public attitudes towards epilepsy. Caveness and Gallup (1980) recording public attitudes towards epilepsy over a 30 year period, reported that although levels of knowledge of epilepsy had remained the same, there was an increasing openness and acceptance towards epilepsy by the general public. This was especially the case in urban areas and among the younger, better educated members of society. One example of this acceptance is reflected in the dramatic decrease from 24% in 1949, to only 6% in 1979, of study respondents who reported that they would object to their child playing with a child with epilepsy. Support for positive change in public attitudes is also reflected in several parallel studies, conducted in West Germany (Canger & Cornaggia, 1985), Denmark (Jenson & Dam, 1992), Hungary (Mirnics et al., 2000),Canada (Young et al., 2002), and New Zealand (Hills et al., 2002).

On the basis of these studies one might conclude that public attitudes towards people with epilepsy are becoming more enlightened, in the developed world at least; yet 'old' ideas about epilepsy appear to persist, and as such, continue to negatively inform attitudes. Such negative beliefs about people with epilepsy are evidenced in relation to, marriage (Dilorio et al., 2004; Spatt et al., 2005; Guo et al., 2012) and dating (Austin et al., 2002; Guo et al., 2012); in attributions of insanity (Novotna & Rektor, 2002) and beliefs about increased personality problems (Jacoby et al., 2004); in perceptions of unreliability and inability to perform normal working and social roles (Dilorio et al., 2004; Jacoby et al., 2004) and in

expressions of nervousness and fear at being around a person with epilepsy (Dilorio et al., 2004). Until society puts epilepsy into its appropriate context, internalised stigma can be expected.

3.4.5.3. Institutionalised stigma

Muhlbauer's third operational level of stigma is embedded in legal discrimination against people with epilepsy. As previously discussed, this practice dates back centuries and included restrictions on immigration, marriage and fertility. Even today, two obvious areas of restriction remain; employment and driving. In the United Kingdom for example, there is a legislative ban on people with epilepsy entering the 'armed' or 'uniformed' forces and their access to professions such as teaching and medicine may be limited (Jacoby & Austin, 2007). There is also a legislative ban on people with epilepsy driving as an occupation as well as an enforced personal responsibility to inform the Driver and Vehicle Licensing Agency (DVLA) of their condition. The DVLA rules are complex (DVLA, 2014) but in summary (Epilepsy Action, 2007), those persons with continuing seizures or those who are within six months of a change in medication may have their license revoked. A person must be free of a 'daytime' seizure for 12 months or had only 'sleep' seizures for three years or more before being eligible to apply for a driving license. There is an ongoing debate in bioethics over who should bear the burden of ensuring that a person with epilepsy does not drive a car or fly an airplane; currently however, the extent of this legislative surveillance is such, that should a doctor become aware that a patient with uncontrolled epilepsy is continuing to drive and, after reminding the patient of their responsibility, he / she has a duty to break confidentiality and inform the DVLA.

3.5. Chapter summary

By mapping epilepsy to its ancestral, cultural, medical and social milieu it becomes clear that the experience of epilepsy may be far greater than its pathology and far more complex than its pharmacological treatment. There is evidence that individuals with epilepsy are still regarded with hostility worldwide. And, although stigma towards epilepsy has reduced over time, specific misconceptions remain which, unfortunately, have the potential to perpetuate discrimination towards people with epilepsy (Reis, 2001). It is important to remain mindful that attitude surveys, with their limitations (social acquiescence may prevent members of the public from accurately reporting levels of discrimination), can lead to distrust in their reports of widespread public understanding of the condition and perhaps

serve only as an estimate of public sentiment, rather than a true reflection of public behaviour.

The often reported non-rational approach to epilepsy stems not only from within the public domain, but in some instances, from medical professionals as well. The ensuing stigma associated with epilepsy poses threats to the identity, self-esteem, security, and life opportunities of those with epilepsy and as such requires health professionals to accept the principles of co-participation in care (Scambler, 1998). Schneider and Conrad (1983) note that an individuals' experience of their epilepsy is not just simply a direct result of the medical severity of their seizures but is also related to the way in which they perceive the medical, personal and social impact of epilepsy and the coping strategies they employ in dealing with these realities. This demands health professionals adopt a holistic rather than a biomedical approach, with the emphasis on informing, advising and helping, not merely managing disease, and developing counselling skills to compliment technical skills as well as advising on a range of coping strategies (Scambler, 1994). This approach however, presupposes awareness of the lived-experience of epilepsy and the salience of phenomena such as stigma.

To aid awareness and understanding I argued in Chapter Two for the need to bring individuals, with their particular experiences of epilepsy into focus. I advocated narrative inquiry as a way to seeing epilepsy from the perspective of the sufferer; a form of inquiry in which the human subject rather than the pathology is the central character:

> *"To restore the human subject at the centre – the suffering, afflicted, fighting, human subject – we must deepen a case history to a narrative or tale; only then do we have a "who" as well as a "what", a real person, a patient, in relation to disease – in relation to the physical".* (Sacks, 1987, pviii).

The following chapter therefore, serves to introduce those individuals with epilepsy, who told *their stories* of this experience.

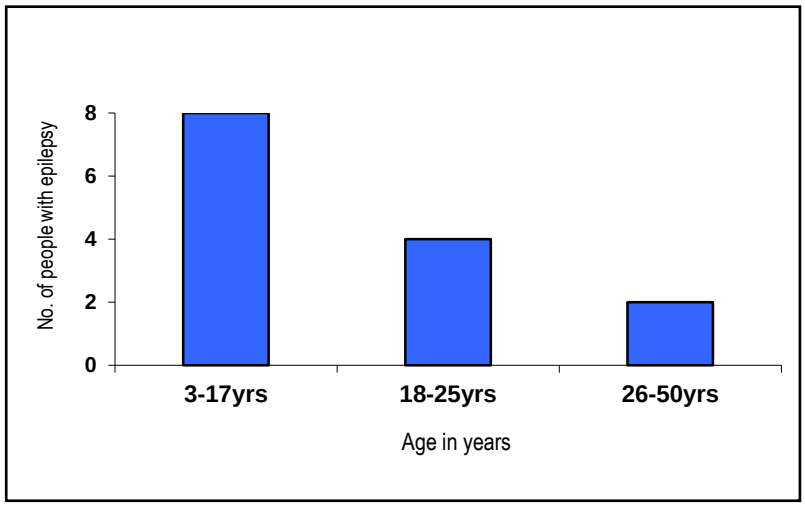
CHAPTER FOUR

4. The story tellers

4.1 Data and context

Within the course of this study I met at least twice with the fourteen study participants[10]. Geographically, my participants resided across inner city and urban Liverpool, rural Cheshire and rural Lancashire and thus reflect diverse socio-economic circumstances. Six of my participants, ***Fran***[11], ***Charles***, ***Ashley***, ***Stuart***, ***Martin*** and ***Yolande*** were currently living with married spouses or in a civil partnership; some were in their first marriages, others in subsequent marriages. Four participants, ***Karen, William, Ricky*** and ***June*** were all divorced and lived alone. ***Larry*** had been a widower for a number of years and my remaining three participants ***Alan, Jessica*** and ***Brenda*** were single.

Figure 5: Age of person with epilepsy at onset of condition



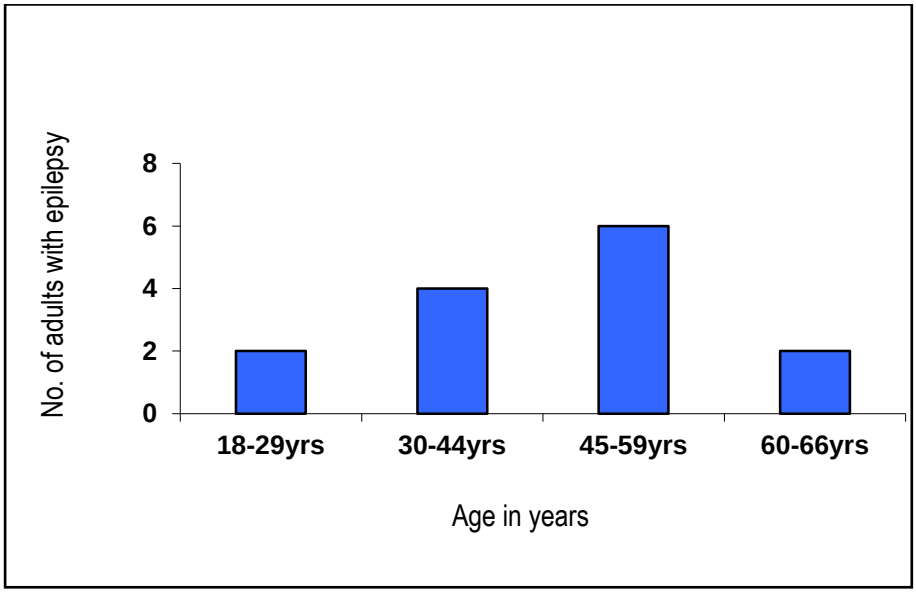
Our narrative encounters began during the pilot phase of the study in the summer of 2005 and continued until winter 2007 and reflect my participants' recent and more distant

[10] A summary is provided at Appendix 8 to indicate the number, approximate timing, focus and content of all data collection points on a participant by participant basis.

[11] Pseudonyms have been assigned to study participants and their family members in order to preserve their anonymity.

experiences of life with epilepsy. The age at onset of epilepsy, as described by my participants, ranged between 3 and 47 years of age (Figure 5); and the age at time of first interview ranged from 18 to 66 years old (Figure 6). All of my participants were, to varying degrees, still affected by their condition; the duration of which ranged between 3 and 58 years (Figure 7).

Figure 6: Age of person with epilepsy at time of 1st interview



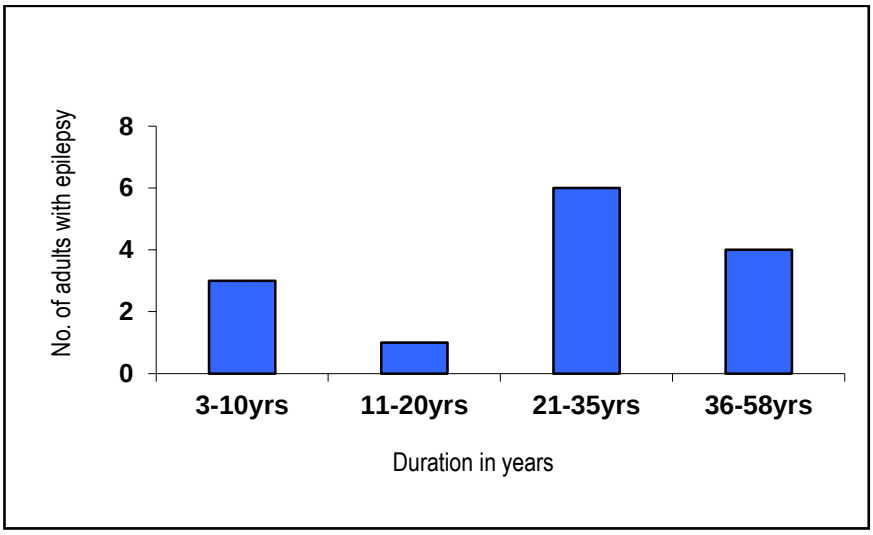
Often participants described events and symptoms which had occurred prior to them receiving a medical diagnosis of epilepsy, which on reflection they attributed to their condition. Thus, their epilepsy career may appear longer than if the point at which they were given 'formal diagnoses' was used as the starting point for the onset of their condition.

As the focus of this study was phenomenological in nature, I did not directly elicit medical information in relation to either seizure classification[12] or severity. However, through their stories I learnt that four of my participants had previously undergone resective brain surgery; all were still taking at least one anti-epileptic drug, some a combination of anti-epileptic drugs, and most had experienced severe episodes of either physical and / or social disruption during the course of living and coping with their epilepsy.

[12] A definition of the lay and medical terms used within the context of this study is provided in the Glossary of Terms.

Collectively these stories comprised an engaging and a poignant account which revealed the difficulties, achievements, uncertainties and hopes of my participants as they experienced their lives with epilepsy; as well as their views on a number of key issues, including, for example, seizure occurrence and control, healthcare intervention, information management and stigma, family life, employment, and driving. For several, the physical and psychosocial impact of their epilepsy still negatively affected their lives, while others felt more able to participate in a 'normal life'.

Figure 7: Duration of epilepsy



My methodological approach however, does not rely on generalisations and while the previous information serves as an accurate overview of the adults with epilepsy participating in this study, it does little to promote their authenticity as individuals. My concern here is to illuminate these adults as 'real people' living their every-day lives with epilepsy, and as experts in the field of their own experience. I therefore continue this account with an introduction to the 'real people'; those individuals with epilepsy who told *their* stories of this experience…

4.2. The story tellers

Alan

Alan, a teenager and my youngest participant was eighteen years old. He lived at home with his Mum, Dad and older brother in a large detached house in a village outside Chester. The family was well educated; Alan's mum tells of her recent thesis submission for her PhD in Business Management, and a large framed photograph of Alan's brother, donning

graduation cap and gown, took pride of place on the lounge wall. Alan's father, following the success of his own business, had retired early; he and Alan enjoyed spending time together on the golf course.

During the chatter of my first visit Alan's father expressed concern that I was doing the wrong study – he strongly suggested I should be interviewing *"family members who have to cope with caring for someone with epilepsy".* Alan however, despite his father's reservations, remained adamant about his wish to participate in the current study. I sensed an unspoken tension of wills between the two of them as I worked hard to allay his father's concerns. Through continued discussion I was able to re-emphasise my own study objectives and Alan's father came to understand that I wasn't doing the wrong study, rather a different study. On my next visit to the family home I was able to speak with Alan alone. In the absence of his father he did not display the same social reserve; rather he was a candid young man, who was as articulate as he was humorous and over the next two hours I came to learn a little of Alan's history.

He explained that he was thirteen or fourteen years old when he was diagnosed with epilepsy. His parents had taken him to see the Doctor because he had been experiencing "*these attacks*" in which *"my heart started racing and I started shaking and feeling woozy*" - on a bad day these attacks could occur as frequently as twenty times. Prior to his diagnosis Alan had led a happy life in a *"normal childhood"* but this was all *"shut down" on*ce he had epilepsy. Subsequently, Alan experienced difficulties in school. He tells of how he felt different, how he lost confidence, how he was concerned about what friends and fellow students thought of him when he had attacks in school, and how he had problems concentrating because his medication always made him feel tired. Problems with his short term memory had led to a decline in the standard of both his school work and his homework. As a consequence of this Alan often found himself on "*report*" and his Mum had been called into the school to discuss his behaviour on more than one occasion; a situation which at the time created family tension and led to arguments with his parents.

In his final year at school Alan underwent resective brain surgery for his epilepsy. He recounts how his school friends appeared to have "*moved on"* during his absence which made him feel like an "*outsider*" on his return to school. He also tells of how he was bullied by some of his peers which led him to withdraw socially and keep himself to himself. However, according to Alan, having the operation was absolutely the right thing to do for as

he remarks, *"when I got diagnosed with epilepsy, it felt like the family got diagnosed with it as well because they had to live with it".* Now, he felt able to get on with his life, start making something of himself and his parents could stop their constant worrying. Alan expressed concern about his parent's protectiveness towards him, and especially disliked it when they made "*a fuss"* in response to one of his anxiety attacks; for this was a situation he liked to manage himself. Alan's current position was that he no longer perceived epilepsy as a threat in his life because his seizures had been reduced. Now he does not have seizures when he is awake; only experiencing, what he prefers to call *"anxiety attacks" as* he wakes.

At the time of this interview Alan had been at college for two years studying art and music technology. He viewed this environment as a new start; an opportunity to accomplish things by himself and somewhere that enabled him to show others the *"real me"* without them knowing his past. College was also the place where Alan established new friendships and met his girlfriend, about whom he spoke fondly.

And what of the future? Alan spoke here with clarity. First and foremost he was learning to drive - the DVLA having recently re-issued him with a provisional driving licence - secondly; he wanted to negotiate greater independence for himself which he intended to achieve by showing his parents that he could behave responsibly, and that they could trust him to make his own decisions about how to manage his life. Following in his father's footsteps, his longer term ambitions revolve around setting up his own business, although he says as yet he is not quite sure in what.

Brenda

Brenda, having never married, was a single mum of forty. She lived with her twelve year old son Peter, in a traditional, well-appointed terraced house, situated in rural Lancashire. As she opened the door to our first encounter I remember thinking Brenda looked younger than her age; her hair and make-up was immaculate. It was only later that I came to understand the meaning behind my observation and the importance Brenda placed on her physical appearance and early morning make-up routine.

Brenda was a friendly, caring and warm-hearted woman, and I enjoyed our conversations. As we talked I learned that she had struggled with the demands of work and single parenthood, recognising that much of what she had achieved would not have been possible

without the constant support of her family; in particular the strong emotional support she received from her brother and her sister.

Brenda was diagnosed with epilepsy at the age of twelve. She had blacked-out and wet herself in class at school. According to Brenda these episodic symptoms had subsided after about seven weeks and her General Practitioner subsequently stopped her anti-epileptic medication. Brenda explained she *"was fine through secondary school"* but epilepsy came back at the age of seventeen; she recalled wetting herself at the bus stop outside the college where she was a pre-nursing student. The embarrassment of this occurrence and the opinion of her college tutor that because of epilepsy she would be unable to become a nurse had been difficult for Brenda to accept; she felt forced to leave college and went to work in a factory. Brenda recounted few details about her experiences during the following two years other than to express "*at eighteen I was suicidal. I rebelled against it* [epilepsy]*".*

At nineteen Brenda was employed as a carer in a children's home where she worked for five years. After a short period of unemployment, she became an auxiliary nurse - a post which she still held at the time of our encounters - caring for patients with dementia. Brenda was particularly conscious of her sickness episodes from work and how her epilepsy might be perceived as representing a profound threat to her competence to perform as a fully-fledged member of a working team. At this time, Brenda was negotiating a retirement package on the grounds of ill health, she acknowledged her current condition prevented her return to work but at the same time expressed how retirement at the age of forty seemed strange; a concept she was still coming to terms with. While this situation would enable her to spend more time with her son Peter, she also expressed concern about her potential loss of income and her ability to manage financially as a single mum.

Also of concern to Brenda was her fear of how her epilepsy might have compromised the life and well-being of her son, articulating: "*what I go through, he goes through"*. Her limited response to anti-epileptic drug treatment and lack of seizure remittance following surgical intervention for her epilepsy meant Brenda's seizures were unpredictable, frequent and often severe. The physical and emotional intrusiveness of her symptoms remained evident as Brenda spoke movingly of the times she had "*felt like an unfit mother*" - the time she fell down the stairs with Peter in her arms when he was younger; the time she scalded her groin with boiling water and spent weeks in hospital; the times Peter was unable to

have his friends to stay because she had felt unwell or was too tired to cope with the disruption; and the time she fell on to the open fire in the lounge.

It was this latest accident that prevented Brenda's return to work and had precipitated early retirement negotiations on the grounds of ill health with her current employer; for she sustained serious burns to her face and left hand, recovery from which had required prolonged hospital admission and full-thickness skin grafts. Brenda was still working hard towards acceptance of these recent injuries. Despite her openness, however, she was not immune to the social construction of femininity and its accompanying emphasis on physical appearance; that which having epilepsy had compromised. Aware of the social pressure placed on females to conform to principles of attractiveness, she movingly discussed the ever-present emotional impact of her facial appearance: *"I look in the mirror every morning and sometimes I think well, I don't look any different really…But I am aware, it's like in a morning I have the curtains shut until I get me makeup on. I couldn't walk out of the house without me makeup, but if you saw what it were like underneath this, you'd understand were I was coming from".*

These recent events had been especially traumatic for both Brenda and Peter, and Brenda viewed the camaraderie and support of their local Young Carers Organisation as a critical resource for Peter. Brenda had a realistic view of her epilepsy and its severity and her devotion to her son and his reciprocal emotional and practical support were means by which they "*get through it* [epilepsy] *together*". As Brenda said, her future remains unknown, but by taking care of herself, enjoying the company of her son Peter, and actively occupying the time afforded her through early retirement she is living with epilepsy as best she can.

Jessica

Jessica, like Alan, lived at home with her parents and two younger brothers. Following a night out with friends Jessica recounted how she had apparently - because she has no recollection of the event herself - collapsed in the bathroom. She recalls how she awoke in bed the next morning with *"a horrendous headache"*. The initial reaction of her parents had been that she had taken drugs or was drunk, but as Jessica explains: "*I knew when I woke up feeling rough it wasn't a hangover, it was something not right!"* At seventeen, according to Jessica, she was diagnosed with *"juvenile myoclonic epilepsy*".

Jessica remembers always being "*sort of clumsy as a kid"*; recounting the frequency with which she would drop the telephone in the middle of conversations with friends, and how she constantly knocked over drinks, - actions she now attributed to her epilepsy, but which at the time she understood as *"the dizzy moments"* of just being Jessica. She explained that because in her mind nothing had really changed, her initial response to diagnosis was one of frustration and annoyance as loss of control over certain aspects of her life became apparent - for Jessica having the label of epilepsy was "*like having your wings clipped".* In articulating this frustration and annoyance I learnt from Jessica how she had to stop taking driving lessons at a time when all her friends were passing their driving tests and buying their own cars; how she battled with the concerns and "*over protectiveness"* of her parents in her effort to maintain independence; and how - having been told by her medical consultant she would probably be on medication for the rest of her life, she struggled to overcome her phobia of choking when trying to swallow tablets.

At twenty-two Jessica discovered quite by accident that one potential side effect of her medication – Epilim (Sodium Valproate) – was polycystic ovaries. She knew she wanted children; Jessica described however, how information about reproductive health had not been discussed as part of her treatment management for epilepsy. Concerned that by taking this drug she was potentially "*storing up trouble for the future"* she requested a change of medication. According to Jessica this process of being weaned off Epilim and the staged introduction of alternative anti-epileptic medications led to a series of physical, mental and emotional side effects which took a toll on her health. She reports at length symptoms which intensified over a period of several months and included: pins and needles, numbness and intermittent loss of movement in her right arm and leg, bladder weakness, heart arrhythmias, breathlessness, rapid loss of weight, poor memory and mental confusion, all of which led ultimately to her admission into hospital. Jessica's account of this four-week hospital experience echoes both her dissatisfaction with the medical care she received and the emotional turmoil she suffered. Jessica describes how, following her discharge from hospital, her efforts to re-gain bodily control left her feeling desperate and suicidal; this prompted her to seek counselling and psychotherapy. Therapy, according to Jessica, has helped with her coping; she reflects*: "although epilepsy took my life for a couple of years while all the trauma was going on, it's never stopped me doing anything that I've wanted to do"*.

This reflection certainly appeared true of Jessica; for at the age of twenty-six when we first met, she projected herself as a well-educated and articulate young woman. Despite the physical and emotional assault that epilepsy represented, she had striven successfully to complete her academic studies and her professional training and was currently engaged in full-time employment as a court appointed probation officer. In fact, it was in her office at the Magistrates Court that our first meeting took place. I can only speculate about Jessica's motivations for inviting me to such a busy environment in which to conduct our discussion, but what became evident about this circumstance was that the background reality of the occasion provided much of the pre-narrative material for some of her stories. Both on this occasion and in our subsequent discussion at her friend's home, Jessica expressed how important her work was to her. She often worked with marginalised people, listening to and referring them on, as appropriate, to social and medical services. According to Jessica it was this aspect of her work from which she derived greatest satisfaction and an aspect which helped her to cope with her own condition. At the same time, these experiences of work were somewhat paradoxical; for Jessica's work stories also reflected the personal, physical and emotional struggles she encountered in managing her role of worker. Of particular concern here were her absences from work due to episodes of sickness, the inconvenience of not being able to drive to other venues for staff meetings and interviews with clients, and in Jessica's opinion, the unnecessary restrictions placed upon her by her previous boss, all of which required her to constantly legitimise her place within the workforce. Both here, as with other identified markers of life-disruption, Jessica's response was testament to her ability to persevere in the face of difficult, and at times overwhelming circumstances.

Fran

Fran was forty-two years old when we met. I interviewed her in her home, where she resided with her husband and three young sons. They lived in a beautiful, spacious, detached house in a residential area on the outskirts of Liverpool. Although Fran had worked intermittently over previous years as a clerical assistant, the success of her husband's business had assured financial security for the family and Fran had been able to give up work to become a full-time housewife and mother to their boys; the eldest of whom was nine years old.

Fran began our conversation by recalling the occasion of her first fit; it was early morning, her mum had just returned home from working a night shift as a nurse and they were watching the television together on the sofa. The next thing she remembered was *"being brought round".* Fran attributes the onset of this fit to a high temperature (she had been unwell) and a flickering television set. According to Fran, following a series of tests at a children's hospital, she was diagnosed, at the age of eleven years, with *"grand mal epilepsy"* and prescribed the anti-epileptic drug Sodium Valproate (Epilim). Fran explained that having epilepsy didn't really affect her until the occurrence of her second seizure at the age of fifteen years. She was on holiday with her family and on the morning of her seizure everyone had been up early, rushing to catch a train. It was from then on Fran says she came to understand her seizures as sleep related: *"It's deprivation of sleep…I've only ever had a fit first thing in the morning"*.

On the one hand, Fran acknowledged her seizures were well controlled - *"I've probably only had about ten fits in the whole of me life"* - she reported that over the years her seizures had reduced in frequency, were less severe and at that time occurred only at night rather than during the day. On the other hand, she claimed this positive clinical picture did little to promote her sense of emotional well-being. For as Fran explained, the worry she experienced in relation to her potential for seizure recurrence was a constant emotional burden which she struggled to cope with. Fran admitted that the "*emotional aspects* [of having epilepsy] *is a big side to it"* for her, - a side which she said had become worse since she got married and had the boys; the fear of having a seizure had taken over her life and was the only thing she constantly thought about. She believed that stress and lack of sleep increased her risk of seizures and her stories spoke of the daily tension she experienced in managing her lifestyle. She told of a life which was measured and organised; of the self-imposed social restrictions she employed as tactics to avert seizure occurrence, and of the subsequent guilt she felt about how her epilepsy impacted on the lives of her husband and her children.

Discussing her illness was a very painful experience for Fran, who became so upset during our conversation that she broke down in tears on more than one occasion, especially when recounting her experiences in relation to motherhood. I learnt how terrified Fran was of being left alone as a new mum in case she should have a fit and hurt her son; of the guilt she experienced as a consequence of her second son being diagnosed with a mild learning disability - which she attributes to the side effects of her anti-epileptic medication; and how

her whole life *"centres around worrying about getting up in the morning because of the boys"*; she worried about whether she would be okay.

Self-image was also important to Fran. She spoke of her fear of seizures in terms of their public visibility; as far as Fran was concerned they signified undignified behaviour, embarrassment and a lack of control. Prior to her marriage, epilepsy was *"like a little secret you've got"* and one she had managed to keep hidden. She didn't disclose she had epilepsy to her husband until after he had witnessed her having a seizure. He, according to Fran, was the only one who really understood how she felt; the thought that anyone, especially her own children, might witness her having a seizure terrified her. The tension in managing this potential risk to her valued social roles of being a wife and mother was further heightened, according to Fran, by the lack of support and understanding shown to her by others; articulating that even her mother believes *"you were lucky to get someone to take you on"*.

Fran hopes that on an emotional level she is better able to deal with having epilepsy, for as she remarked: *"I feel like an emotional wreck"*. She cannot however, see how things can change: *"I kind of feel that my life is on hold"* - she sees her progression towards leading a 'normal' life as hindered.

Charles

Charles had just returned home following his early shift at work when I arrived at the family home – a modest semi-detached house, situated on a housing estate on the outskirts of Cheshire. As we made tea Charles told me he had lived here for a number of years with his wife, his fourteen year old daughter, his son aged eleven years, and the newest addition to their family, Rosie the dog.

Charles' story of epilepsy began in 1984 when he was eighteen years old and serving in the Royal Navy. He explained that he shared sleeping quarters with two other lads who, according to Charles, had been forced to call an ambulance in the middle of the night because he had suffered a *"bad"* seizure in his sleep. He had been an aircraft technician and explained that following this incident he was immediately removed from working on the Sea Harriers and sent for a series of investigations to establish the cause of his seizure. These events marked the beginning of a sudden and enforced life-style change for Charles.

Charles told of being called into a room by the Medical Officer to be told he had nocturnal epilepsy – a diagnosis which meant he would be medically discharged from the Royal Navy. Charles recounts his devastation: *"I mean it really upset me…you're just shattered aren't ya? I mean I joined* [the Royal Navy] *because it was something I wanted to do and just to get the diagnosis, the result that you were going to be disabled from the service all in one day, it's just, what can I say, you just don't know what to do".* No other naval career opportunities were available to Charles and within three months he found himself on *"Civvy Street",* isolated from the career and friends he loved, and unemployed.

Charles explained that he wanted to continue working on aircraft and had applied for a position with British Airways. Unfortunately, his naval qualifications were not compatible with Civil Aviation Authority requirements and he ended up working at the factory of a local manufacturing company, mixing ink. This job too carried painful memories for Charles. He continued: *"but I lost this job because I had epilepsy and never put down that I had epilepsy".* Charles explained he had *"fainted"* at work and was taken to hospital. In a subsequent discussion with the factory's Health and Safety Officer Charles disclosed his epilepsy – he asserts the company then instigated dismissal proceedings on the grounds he failed to disclose his epilepsy, on his job application form. Charles's position was that both he and his Union fought for seven months to keep his job, but that his employer was unwilling to negotiate a change of job for him and appeared determined to dismiss him. Charles explained that he had been suspended from work during these discussions; money was limited, so when the company offered him £1000 as *"a good will gesture"*, he accepted and left his job. His options, as he saw them, were limited not least because Charles felt powerless to bring about a change in the attitude of his employer.

At the time of our discussions Charles was forty and had worked for a DIY retailer for a number of years. According to Charles they were an excellent employer, with a disability policy; the fact Charles had epilepsy was not a problem. Charles told of how recently, he had accepted an opportunity to undertake further training to become a staff supervisor. He said he enjoyed the challenges presented by this training although at times it could be stressful. Nevertheless, he was looking forward to the opening of the new store where he was to work as an Early-shift Supervisor. Currently Charles worked part-time; an arrangement which he felt worked well. He was able to care for his children when they returned home from school, prepare the evening meal and take care of some of the domestic chores around the home. Sharing these domestic responsibilities was viewed by

Charles as team work and enabled his wife to remain in full-time employment, a financial necessity.

Charles loved his football. He coached a local schoolboy team - in which his son played - on a Wednesday evening and a Saturday morning; a role which he said gave him a great deal of pleasure. In addition, he played football with other trainers and coaches one evening a week. However, in establishing both this social role and that of worker for himself Charles was cognizant of the emotional and practical support he constantly received from his wife; acknowledging that without it many of his activities would be curtailed. Although Charles had not had a seizure for over two years, his experience of epilepsy extended beyond such physical manifestations to encompass notions of guilt. He explained how he felt a burden to his wife at times, not least because he was unable to drive.

Ashley

Ashley was in a civil partnership and was mum to a young daughter of eleven years. The family lived in a rented semi-detached house in Wirral, Cheshire. According to Ashley, their house had been made available to them through Social Services because she had epilepsy and because she needed daily practical support from her Mum who lived close by. When we met, Ashley had just celebrated her fortieth birthday and was pleased to be back in work as a part-time hospital domestic, following what she refers to as *"a bad stretch where I was off quite a bit"* .

Ashley's account contains a number of elements around the question of onset, possible causation and treatment of her epilepsy. She said that at the age of seven or eight she had a bang on the head and from then on, according to family members, *"she just used to go blank".* She also suffered febrile convulsions as a baby and her consultant had explained it was her convulsions rather than the bang on her head that had caused her epilepsy. This statement of cause carried significance for Ashley and served to heighten her own situation, for as she explained, *"me sister, she would have been forty-six now…err she died of them* [febrile convulsion]".

According to Ashley, as a child her epilepsy wasn't too bad and she just got on with things but as she got older her epilepsy became worse. Ashley viewed epilepsy as an *"it"*, something characterised as *"horrible"* and *"frightening"*. As a teenager "*it* [epilepsy] *went from petit mal to grand mal"* and she reported the occurrence of seizures as being more

frequent prior to menstruation and at times when she was excited or stressed. She had been frightened to go out in case i*t* happened; fear which she says led to a constant sense of insecurity. Ashley remarked that surprisingly her pregnancy had been unproblematic – apart from her own worries that the anti-epileptic drugs she was taking might harm her baby. However, she reported that after the birth of her daughter her seizures returned as frequently as before, making it difficult for her to secure employment for a number of years.

Recently however, improvements in Ashley's physical and emotional health - as a consequence of surgical intervention for the treatment of her epilepsy - had encouraged her to lead a more active life. Drawing on experiential knowledge Ashley told a number of stories in which she directly compared her pre-operative and post-operative self. These evaluations of difference were used to explain and bring narrative meaning to how things were for her and to her renewed sense of self. I learnt that prior to her surgery Ashley's frequent seizures left her feeling tired and in need of sleep, and how this had led to worry about how dependant she felt she had become on others for support. Ashley had perceived epilepsy as a barrier between her and her partner, often feeling their relationship had become strained: *"he doesn't like to talk about illness…and the seizures you know, he never even looked at me or cuddled me"*. Now, reflecting on her post-operative self, Ashley articulated: *"I'm made up; it's brought me out of meself"*. She explained her seizures had diminished from as many as four or five a day to "*just little feelings"*; that she was less dependant on her mother and young daughter; that her relationship with her husband was more loving; that her sense of insecurity had diminished; and, that her renewed self-confidence had enabled her to socialise with friends and motivated her to follow up her interest in working as a health care assistant - a post for which she was currently in the process of applying for.

In acknowledging her personal progression, Ashley recognised the potential for a different route forward and one which constituted an experience of hope for the future; *"I just keep looking forward basically, I don't look for any anxieties or fears. Just look forward and hope that things will get better all the time"*.

Stuart

Stuart had been married since the age of twenty, and had two grown up sons who lived away from home; one of who was in the army and currently serving in Iraq. He lived with

his wife in a semi-detached house in a residential area, north of the city of Liverpool. When I met Stuart at his home he was friendly, optimistic and articulate; his wife, a full-time college lecturer, was away attending a conference and Stuart told me he welcomed my company and was more than happy to chat.

Stuart explained that there was *"no hint of anything"* until he was about eighteen years old when he collapsed during a night out with his mates at a club in Liverpool. He had no recollection of what had happened but reports that as he was coming round, *"the people around and the bouncers thought I had been on drugs".* He said he had a great group of mates who took him home; returning the following day to explain to his parents what had happened. Stuart reports undergoing a series of tests and brain scans - *"for quite some time they* [the doctors] *thought I had a tumour"* - before eventually being diagnosed with epilepsy.

According to Stuart, the majority and the most severe seizures occurred at night; those he experienced in the day he described as *"dizzy episodes…very petite mal, where you stand there and you loose all awareness of what's around ya"*. However, although his day time seizures were less severe than those occurring at night, Stuart considers the reality of his petite mal attacks just as bad for, *"you've got no power over them, you can be anywhere"*. He went on to explain how his seizures drained him physically and that he always needed to sleep for about an hour after each of his attacks.

Stuart expressed concern that managing the symptoms of his epilepsy was at times problematic, especially in relation to his working life. At sixteen he began his apprentice as an engineer which he said luckily, he had been able to complete. However, after qualifying he left engineering to work in a betting shop. Stuart described this time as a low point in his life; despite the support of his wife, he said he was very depressed. The birth of his two sons signified an emotional turning point for Stuart and the social value he placed on his role as 'family breadwinner' was evidenced in the account of his subsequent return to engineering: "*I was young and I had a young family. I didn't know if I would be out of work. I just wanted to work and I felt if I disclosed it* [having epilepsy]*…the fella who was alright would get it* [the job] *and you wouldn't get it and I had applied for jobs in the past and disclosed it and just got told no because of your epilepsy… I just didn't feel it was worth disclosing. I never felt guilty because I got the job, and eh! I ended staying there for over twenty-five years. I thought if I take me medication I'll be alright".*

During Stuart's twenty-five years as an engineer he was cognizant and appreciative of the friendship and support afforded him by his work colleagues; they drove him to and from work on a daily basis and would cover for him when he had one of his *"dizzy spells"*. Over the years Stuart's work role had changed – he became a Supervisor and a Union Representative – which afforded him the benefit of not directly working with machinery. However, by his late forties Stuart said he had no longer felt able to affirm his position in the work force and had taken steps to negotiate early retirement; he explained, "*(…)then when I started getting them more frequent in work, dropping things, people would notice, I thought, I'm an engineer you know? Can't be sayin sorry about that".* Stuart said he had always tried to be as active as he could in his free time; he enjoyed going on long walks, playing football and going to the match on a Saturday to watch his local football team who he *"worships".* However, I learnt that Stuart's recent stroke and a fracture to his shoulder had considerably restricted his participation in these activities. Now he said he didn't go out on his own; his wife worried and he respected her wish that he should always have someone with him in case anything untoward should happen.

The concern and support afforded Stuart by his wife and his two boys was a continuous thread throughout his story telling; they are a team. Not least in connection with Stuart's health care experiences where he portrayed decision making in relation to his medical encounters as a shared endeavour – "*we decided", "we thought", "we didn't like".* Stuart tells various stories of these experiences accrued over the years, some of which portray physicians in less than a positive light, while others characterise physicians as trustworthy friends; making time to see him and to listen to him.

Reflecting, Stuart admitted that when he was younger he viewed epilepsy as *"extra baggage"* but unlike Fran, said that over the years he had learnt to live with it and to make the best of life. On balance, according to Stuart, he had a good life, had a caring family and he enjoyed spending time with them.

Martin

Martin lived in Local Authority housing on the outskirts of Liverpool. He shared a ground floor flat with his fourth wife Lesley; a very friendly lady who kept Martin and me supplied with endless cups of tea and coffee throughout our meeting. Martin had been a career soldier with eighteen years service and numerous postings to Northern Ireland under his belt. He was fifty-four years old when we met but explained he had been retired for

several years, on the grounds of ill health. Martin recounted his life with epilepsy in three biographically located chapters. Interestingly, he began his narrative in the middle - with a story of diagnosis. He then moved backwards in time to connect early life suffering to his experience of epilepsy before relocating his narrative in the present.

Beginning with the circumstances surrounding his medical diagnosis of epilepsy, I learnt from Martin that during a spell in hospital as an in-patient he had suffered a fit – *"quite a bad one apparently"*. Following a series of tests he said his fit had been medically explained to him as epilepsy. Since that time Martin had experienced occasional fits; some of which "*have been quite bad"* and he told how, as a consequence of injuries related to seizure activity, he was no longer able to fully stretch his back. Reflecting on these events Martin explained that while the events in hospital brought his illness into focus, he believed his epilepsy began many years prior to this formal medical diagnosis - *"It was January, 1974".* The precision of Martin's recall of events and the graphic description he employed in their telling served as powerful indicators of the significance of these unfolding experiences.

In particular, Martin linked the onset of his epilepsy to a traumatic event that occurred when he was twenty-one years old during his service in Northern Ireland as a member of the armed forces: *"There was an accident, a bad accident, well not an accident, a murder. That's when it affected me"*. Martin continued emotionally with a story of how, over his personal radio head set, he heard his best friend shot, remarking: *"he was killed outright".* He talked of the stress, anxiety and fear he endured as a consequence of army life and attributed this trauma to the cause of his epilepsy. Although he wasn't diagnosed with having epilepsy in the army, he now believed he suffered from it during that time; using the metaphor of battle, *"I just battled through it. I believe I battled through it"* to describe how he coped with symptoms such as anxiety which he links to his epilepsy.

Martin explained that even after leaving the army he still experienced episodes of anxiety and episodes of *"recalls of things that happened"*. Army life was traumatic. As well as being responsible for triggering his epilepsy, he further attributes the trauma of army life experiences to his subsequent social circumstances; the difficulties he said he experienced in adjusting to work and life in *"Civvy Street*"; his three divorces; his estranged relationship with his two daughters from his first marriage; and, his alcohol abuse. The latter, Martin acknowledged had probably made his *"fitting"* worse.

Moving to present day accounts, Martin reported he had stopped drinking over six months ago but that his flashbacks of traumatic times and his seizures remained still. He takes his anti-epileptic medication regularly but described this process as a *"six of one and half a dozen of the other"* scenario. He reported being constantly tired as a consequence of his prescription of medication and said he often slept during the day. However, although Martin felt less tired when his medication was reduced he said the frequency of his seizures increased. According to Martin, his fits occurred without warning; he *"always ends up on the floor"* which on occasions has resulted in injuries to his head and back. Recently Martin suffered a stroke; although he has regained physical mobility he doesn't like to be left alone in case something untoward should occur, and he expressed gratitude for the caring support he receives from his wife and neighbours.

Martin told of how he misses going out to work and how having epilepsy has compromised his ability to undertake a job that he was both trained to do and would love to do - an outward bound instructor. By disclosing his epilepsy, according to Martin, his application would have been rejected. He expressed understanding as to why this has to be the case - for having a seizure under these circumstances would compromise not only his own safety but the safety of those he was supervising - nevertheless it was a situation he finds both frustrating and upsetting. For this reason he said he didn't have big ambitions for the future, preferring to set himself a mix of daily tasks and shorter term goals which he said he knows he could achieve. At the time of the interview Martin and his wife were in the process of planning their goal for that year – a trip to Australia to visit his brother.

Yolande

Yolande was fifty-nine years old when we met and lived with her second husband in a first floor flat in a suburb of Liverpool. She was my very first interviewee and as I rang the doorbell I can recall feeling excited by the prospect that, after what had seemed a long period of preparation, my study 'in the field' was about to start. What struck me most profoundly about Yolande – perhaps because it appeared at the time in sharp relief to my own inner sense of excitement – was her portrayal of calmness; she had an ability to talk about quite disturbing incidents in her life in a reflexive, calm and almost 'matter of fact' manner. Her honesty was touching and I appreciated the trust she placed in me as she recounted particular experiences in her life. Presented as an autobiographical account, Yolande's narrative is a life story, which among other things incorporates her experiences

of epilepsy. As our conversations evolved I learnt that epilepsy for Yolande is *"just part of life's rich tapestry"*; something she had coped with alongside other and in most cases more traumatic events in her life. As such epilepsy, according to Yolande, sat well down the *"pecking order"* of things that had to be dealt with.

Yolande opened our conversation with a lengthy story of why at the age of fifteen years she *"thought there was something wrong*". In setting the scene for this story she tells of how the family lived in a large house – it was a long trek from the back parlour to the front bedroom where her cousin, who had come to stay, was sleeping. She had been instructed to take him an early morning cup of tea. According to Yolande, *"Doing anything in that house was like going on safari"*. Yet she was unable to retrace her steps to her cousin's bedroom door that morning - no memory of the walk along the lengthy hallways or of all the stairs she climbed to get there. Yolande says her inability to recall the details of this journey prompted her to think that something must be wrong.

According to Yolande, attending Grammar School and college had been unproblematic. She spoke however of difficult family-life experiences, including her grandfather's death, her mother's depression and of the hardship she had endured in coping with and caring for her mother, her two younger sisters and her younger brother, and her father's abusive behaviour towards both her and her mother. She blamed herself for this latter situation and recounted how she had felt very insecure as a child – for according to Yolande, she had been the reason her parents needed to get married in the first place.

Yolande was retired when we met but had been a junior school teacher. She recalled teaching mathematics to her top infants class when, *"the next thing I knew I woke up in the ambulance man's arms".* Yolande reported being off work for a couple of weeks after that incident and being prescribed Valium for depression by her General Practitioner, which she said she refused to take because she knew she wasn't depressed. By this time Yolande was married and it was her husband who had noticed her have a fit. Following a series of brain scans Yolande said she was diagnosed with epilepsy at the age of twenty-five or twenty-six and prescribed the anti-epileptic drugs Epinutin and Phenobarbitone.

During the years that followed Yolande recounted a number of seizure-related incidents that occurred both at work and socially and spoke of the reactions and attitudes of others. She reported being amazed that some people talked about fits as if they were something unclean and that up until the war people got locked away for having epilepsy. According to

Yolande people who think like that are just ignorant and her position was that having epilepsy didn't bother her. However, as she spoke I sensed a great deal of denial and psychological defence work against stigma in the way Yolande presented herself; appearing to shut herself off from what others might think of her: *"I'm not present when I have a seizure, so I'm not worried by people's reactions".* I wondered perhaps whether this attitude of 'what I don't know doesn't hurt', speaks of dealing with stigma rather than an absence of stigma.

Being married to her first husband had, according to Yolande, been fraught with difficulty. He was distant, unkind and he didn't like going out to work. She had been *"the breadwinner in the family"*. Her husband's lack of interest in family life was only understood by Yolande when she later discovered – as a consequence of his court appearance – that her marriage had been pretence for her husband's illicit homosexual activities. Their subsequent divorce had required Yolande to constantly negotiate the demands of work and home life in an effort to manage the responsibilities of bringing up their son on her own.

Yolande met her second husband Sam through work and spoke fondly of their eighteen years together. However Sam's declining health had, according to Yolande, forced changes to their routines and in the way they managed their daily activities. Now she often had to go out alone; a situation which caused her concern in case she should have a fit, and she spoke of missing the support previously afforded her by her husband. This disruption to routine and to their relationship was a consequence of Sam having Alzheimer's disease; she explained: *"he's totally bewildered now…he's just not the same person he was twelve months ago".* Yolande's concerns and commitments now focus on the care and needs of her husband: *"I can get by, I can survive. He's the most important one now".*

Larry

Larry was a widower when we met. He lived in Merseyside in Local Authority housing which comprised a number of one-bedroom flats and shared community day rooms. The complex, where Larry had been a resident for the past seven years, afforded him the support of a 24 hour 'call-out' system and a residential care warden who lived in. Although Larry looked older than his years he told me that at sixty-one he was in fact the *"youngest resident"* - a title which he believed afforded him many benefits for he was constantly mothered by the older female residents of this close-knit community.

Much like Yolande, Larry's story was a life story that incorporated other things along with his experiences of epilepsy. Unlike Yolande however, Larry's telling resonated with a deep sense of loss; the loss of family love and security from his early childhood days - memories of which remained cherished by Larry. In recounting difficult experiences from his past, Larry's experience of epilepsy played a role but it was a role subsumed in a wider context of personal suffering; a stressful relationship with his *'alcoholic'* wife, the fragmented relationship and abuse from one of his two adopted sons, and his recent onset of diabetes. Through his stories it became clear that Larry placed great value on his current surroundings which he saw as a secure and supportive community.

His story began with recollections of "*not feeling so good"* which stemmed back to his early childhood: "*Well I used to wake up during the middle of the night and used to have to go into me mum and dad's room, … said are ya not so good? And I said no not that good, and said come in, come in then me lad and I could get in between them and they were sound. That's me champion, I got back to sleep again and I felt comfortable".* Here as in other descriptions of his seizures Larry didn't draw on medical terminology but used his background knowledge of everyday discourse to refer to this experience in an indefinite way; there was talk of "*not feeling so good"*, "*feeling dizzy", "shivering" and "drifting away"* - talk which was embedded in stories of comfort and security of early family life, protection and understanding from school teachers and friends, and later in his life, the support and positive attitude afforded him by his work colleagues and his employer.

Larry's reflective evaluations served not only as an interpretive framework for his understanding of the meaning of epilepsy but were presented as illustrations of sharp contrast to stories of later psychological suffering. These stories were framed around his marriage and subsequent family life: "(…) *actually I've had a horrible marriage, to tell you truth, I've had a really horrible marriage. My wife was alcoholic. She died only about fifty odd. Everybody says, we had a lovely house, hundred and odd thousand. I paid for it and everything, it was a great house. And she wouldn't have children, we adopted two and after I'd sold the house and everything, I couldn't live in it again, I sold the house, and me son, I paid all his credit cards off and everything, £18,000 was the credit cards …I don't see him, I don't see him at all".* Larry's stories of family distress were set against a backdrop of personal endeavour to be a good breadwinner, husband and father. They spoke of the stress of adopting the boys; of the struggle to cope with their unruly behaviour; of his wife's behaviour and death; of his upset over the practiced financial deceit of one of his sons; and,

of his sadness at never having seen his grandson, - such stories continually intercepted positive discussion of Larry's preference for how life was lived now.

In describing how life was lived now Larry remarked he was able to maintain his independence within a supportive, community environment. His daily social activities revolved around environments and people he knew; the local pub for *"a pint of lemonade"*, the café for his *"big breakfast"*, and the betting shop – his familiarity with these surroundings and the predictability of peoples' positive behaviour towards him, according to Larry, gave him the confidence to go out; for he knew they would support him when he was "*not so good"*.

Larry's story was hard to hear and because of his constant digressions, at times difficult to follow. However, I came to realise - several readings of the interview transcript later - that the point of the unfolding plot appears to be restoration of normative values that Larry identifies and holds dear. He is now where he wants to be: "*I'm doing alright with these people in here, it's the best thing I ever did. I must admit, I would, if I went in rented accommodation outside, where there wasn't people like Lynne* [resident warden] *downstairs, or Mabel* [co-resident and friend] *to go and talk to next door I wouldn't, I wouldn't like it at all, because she's like a mother to me. She's about seventy odd and she's like me mother, she talks all day to ya and everything, come in love, you know, things like that. Lynne downstairs, she's brilliant"*.

Karen

Karen lived on the Wirral but wanted to meet with me in Liverpool; having been re-issued her driving licence she said our meeting would provide *"a good excuse for a drive out".* We met over lunch in the restaurant at the Anglican Cathedral. I recall from my diary notes that Karen dominated our conversation with talk of her interest and eagerness to participate in this study. Although currently on long-term sick leave she believed her experience of work in the pharmaceutical industry and as an assistant social worker, and my nursing background meant we had health care in common which lent itself to a shared understanding; articulated in comments such as, *"(…) you'll know where I'm coming from"*. Researchers, on the other hand, had their own agenda, according to Karen - it was all about the numbers; she described the co-participation aspects of this project as *"an enlightened approach"*. During the course of this encounter Karen continued to focus on my nursing background; talking to me about her condition would probably make her cry, which up until

now only her therapist had enabled her to do. We agreed to meet again; however, my concern that Karen might view our meetings as clinical encounters required I re-enforce the fact while she might benefit from being able to tell her own story of having epilepsy, she should not view our discussions in terms of psychotherapy.

Karen's choice of venue for our subsequent meeting was a 'quiet room' at the University where I worked. I learnt she was forty-seven years old, had no children, was divorced from her husband, and, apart from the company of her two dogs - who she said she loved dearly - she lived alone. Karen reported her first seizure occurred at the age of twenty-eight during a night out at the squash club. She explained, *"I don't know what the hell it was, hadn't been drinking…and then something happened, don't know what it was. I wasn't around. I wasn't there".* As Karen continued with her account, I found our conversation emotionally challenging for a number of reasons. Karen's narrative appeared to lack coherence and at times was difficult to follow. Her story telling frequently changed direction and she often lost the thread of her thoughts. In searching, as she put it, for *"lost words"* she would often seek confirmation of where she was up to in our conversation. Karen acknowledged that, *"holding on to conversation was difficult";* she preferred at times to be alone. She looked for possible causes: Did it have something to do with her short-term memory deficit? Was communicating difficult because of her episodes of depression? She attributed these mental and emotional symptoms to her resective brain surgery six years previously. Depression, according to Karen, had also been responsible for her extended sick leave from work and her *"incapacity benefit".*

Karen explained over the years she had been prescribed various types of anti-epileptic medication, none of which had been entirely effective. She recounted several seizure events that occurred both at work and socially, and, on more than one occasion, while driving. However, in reviewing her lifestyle Karen recognised her haphazard approach to taking medication as a contributing factor to the frequency and severity of her seizure occurrences. She explained that as an avid and competitive squash player she had often delayed or omitted to take her drugs in favour of playing a match. Karen recalled the turning point in this cycle of events - reading a newspaper article about brain surgery for the treatment of epilepsy. Eager to be free from epilepsy she reported how from then on *"the whole aim in my life was the operation"* which she said she demanded from her General Practitioner.

What then followed was a collection of inter-related stories in which Karen described at length, the pre-operative tests which led up to her resective brain surgery, her experiences of a difficult and prolonged hospital stay, her rapid post-operative weight loss, the emotional trauma of still suffering seizures following surgical intervention and a poignant story of a planned suicide and the reason why she failed to carry this out. Reflecting on these traumatic events, Karen reported psychotherapy had helped in enabling her to cope better. She also told of a number of lifestyle changes. At the time of our encounters, Karen participated in dog agility events instead of playing squash - an activity that enabled her to maintain her competitiveness but one that was less physically demanding than playing squash. She also volunteered at a local support group for people with epilepsy, expressing satisfaction from the ability to help others; regularly took her anti-epileptic medication; and, maintained a comprehensive daily diary to assist with plugging the gaps in her memory. Reflecting positively on the lifestyle changes she had instigated, Karen reported being seizure free for over twelve months.

William

William too was divorced and lived alone in a terraced house on the outskirts of Liverpool. He was fifty years old when we met and his three-year history of epilepsy was the shortest in the study sample. He was employed by Royal Mail. Coincidentally the university building where I worked was part of his delivery route and occasionally he *"just popped in for coffee and a chat"* while out on his round. These conversations were for the most part just chat; the weather; friendly discussion of his love - and my indifference - of football and general talk about the progress of my project. However, on more than one occasion William expressed concern that his story of epilepsy was short-lived and as such might prove not to be particularly interesting. He was back at work and according to William, his epilepsy wasn't a problem. Having assured him that his understanding and experiences of epilepsy were important and would contribute to the already diverse 'stories of epilepsy' collected thus far, I arranged to meet with him again at his home later that week.

I learnt from William that he was driving his postal delivery van when – due to the sudden onset of what he came to learn later was a seizure – he lost control of the vehicle, and drove into iron railings at the side of the road. He remembered coming round in the back of the ambulance but had no recollection of either the accident itself or the events that led up to it. William explained that according to his colleague who was in the van at the time:

"I just started shaking and sort of convulsing". As a result of this accident William sustained an injury to his back and was off work for four months. His second and last seizure occurred two weeks after his return to work: *"I was sorting* [the letters] *away and the next thing bang…"* William remarked that following his traffic accident no one at the hospital mentioned anything about epilepsy, however following this latter event he underwent a series of tests and was told that his seizures were *"epileptic fits"*.

Following his diagnosis of epilepsy William recalled his main concern: *"(…) when he* (consultant) *said you're going to have to tell the DVLA, I realised I was going to lose me licence for twelve months and I couldn't do me normal job in work that bothered me more"*. However, he went on to explain that both his employer and his colleagues had been very supportive – it was agreed that he could swap his postal round which required a van driver with the 'walking round' of a colleague. This offer to 'swap' was a great option according to William for it not only enabled him to continue working but he was also able to remain working within his own team, "*with the lads"* he knew.

Following his diagnosis, William reported he was proactive in seeking out information both about epilepsy in general and in relation to the particulars of his own clinical condition. He was confident in the explanations offered by his consultant (he had been informed his epilepsy had probably been present from an early age and considered himself fortunate not to have suffered a seizure sooner) and drew also on information from other sources to develop his knowledge. He spoke about visiting a local epilepsy advice centre and talking with volunteers, reading information leaflets, and searching the internet. William was taking what he referred to as a "*logical approach"* to understanding his potential future clinical situation and a situation he evaluated in a positive light. According to William epilepsy was controllable; he viewed his own seizure experiences as a brief interruption to business as usual. However, his understanding of the condition also enabled him to articulate how epilepsy, in less positive clinical and social circumstance might have impacted on his work and his social life. On balance however, he remained optimistic. The DVLA had given him approval to drive once again, he would soon get his old postal round back and he remained confident that with the correct medication he would remain seizure free.

Ricky

Ricky on the other hand viewed his future less optimistically. He had been unable to sustain employment due to the frequency of his seizures and was currently unemployed and on sickness benefit. I met Ricky in his home, a rented first-floor flat in a suburb of Liverpool. He was forty-one years old and lived alone. As a divorced middle-aged father of two, he described how he enjoyed the company of his children, Jason and Laura, when they came to stay, but that his '*absences*' caused him increased anxiety in relation to his ability to care for them appropriately during their visits.

Early in our conversation Ricky recounted an incident, at the age of twenty, in which he said he nearly got himself killed. He was leaving the supermarket where he worked and walked unknowingly across a busy eight-lane dual carriage way, and in doing so narrowly missed being run over. Reflecting on earlier life accident events, Ricky acknowledged this incident may not have been the first consequence of having epilepsy; however it was the event that prompted his seeking medical advice and the event that had consequently led to his diagnosis. Ricky presented this incident as threat to his very existence, and as such served to establish early in his narrative a thematic focus revolving around his perceived vulnerability to risk. His notions of risk appeared to be born out of what I shall describe as periods of 'timeless space' which interrupted Ricky's daily activities, and in which he described entering a world of his own; time which he could not account for and a world in which he was unable to recall his actions: "(…)*I just seem to go into one and then come back out of it and I don't know I've had one. I'm the only one who doesn't know what's happened"*.

Ricky told of his concern about what *"might happen"* during one of his *"black-outs",* articulating the cumulative effects of worry in various stories of self-restriction. He spoke of what he cannot do, including paid or voluntary work, driving and cycling; as well as how he limited the boundaries around what he can do. He reported his unease with social interaction outside family and close friends, for he was fearful of what he might say or do, and also of what others might think or do in response to his behaviour. He explained because he had no idea that his *"absence"* had occurred or that any problems may have ensued as a consequence, he found it difficult to know how to act - he couldn't put things right: "*Its only like if people tell me but as I say most people won't tell you they just sort of*

look at ya as if you're weirdo or something…like you are a bit weird, and if they don't tell me what's happened I don't know myself".

In managing *"absences"* as a symptom of his epilepsy, Ricky's repetitive use of the terms *risk*, *fear*, *scared* and his expressed need for supervision not only made explicit his own sense of vulnerability but encompassed an additional moral dimension. Ricky's awareness that his own illness might compromise the wellbeing of others was evidenced in talk about his perceived inadequacy in the role of parent. He questioned his ability to keep his children safe and acknowledged that sometimes his children needed to take on the role of being the adult. He was also cognizant of the additional emotional and care burden responsibilities he believed having epilepsy placed on his ex-wife and his current partner of over two years. The self-limiting tactics of Ricky's epilepsy management meant that he always had to behave in a manner that was sensible and guarded; there was no room for spontaneity in his life and he could not envision a future beyond contingencies of day to day management of self. For as he reported: "*I'm stuck in a rut…just going back to the hospital all the time, just waiting for them to try and find something out. To try and cure it. I just do the same things all the time*".

Ricky reported his anti-epileptic drug treatment as not entirely successful in controlling his seizures. Despite the fact he had tried many different kinds of drugs and had participated in a clinical drug trial he said his condition remained the same. However, surgical intervention as a potential treatment option for his epilepsy, suggested to him by his medical consultant, was not, according to Ricky, an option he was willing to try or a risk he was prepared to take, for as he articulated: *"I said, you're not messing with me brain for 70%* [potential %age for successful clinical outcome]". Although Ricky acknowledged his consultant had *"tried everything"* his experiences related to the medical management of his epilepsy were framed within a repetitive life cycle of 'sameness':

> "*You've been going for twelve, fourteen years and it's still the same…they've got the notes out and what about the tablets? and you go well it's still the same…OK try with these, the next time it's still the same, still the same…its all medicine, medicine all the time its nothing to do with communicating, or them writing down like day to day stuff about how it really does effect yer".*

According to Ricky he was *"just stuck in a rut you just get used to over the years".* Like Fran, Ricky perceived his progression towards leading a 'normal' life as hindered.

June

At sixty-six years old ***June*** was the eldest of my participants. She was divorced from her husband and apart from the company of Birdie, her parakeet, she lived alone. From my diary notes I can recall sitting in the nicely furnished, tidy living room of her first floor flat, located in a pleasant residential area on the outskirts of Liverpool. June, a quietly spoken, unassuming lady was immediately apologetic for the absence of her *"gentleman friend"* [due to a prior engagement] who she had wanted me to meet as she felt he would be better able to explain how she went when she *"took a blackout"*. Over a pot of tea I chatted casually with June for some time - I was keen to assure her of the importance of her own interpretation of her experiences. Later, when I asked her 'could you tell me when you became aware that something might be wrong?' June said she was in her early twenties when she awoke one night to find an ambulance man standing over her bed. As June spoke the surprise of this situation remained evident in her tone. With no recollection of the preceding event, June says she accused her husband of joking when he explained about her having a fit and her response at the time had been to just turn over in bed and go back to sleep. However, June went on to explain that soon it became apparent that having a fit wasn't a joke, neither was it a one-off event as she had first thought: *"it went to blackouts. I'd be just sitting there watching the television and just go blank".* At the time June recalled thinking the sudden onset of her blackouts seemed strange, for up until that point she had been perfectly fine. In searching for a plausible explanation June pinpointed a prior experience – the birth of her son three years earlier. Her son had been delivered by caesarean section operation and June asserted her blackouts were the consequence of being administered anaesthetic gas.

According to June, "*having blackouts is worse than having fits"*. She went on to explain that this was because she had no idea when a blackout would occur and that for her this situation was more dangerous. She continued: *"I'd walk over the road in front of cars and buses and me mind 'ed blackout. I'd come round to find the drivers screaming at me; 'Stupid bitch, why don't you look where you're going!'".* June said she worried about how she would cope, but her only choice had been to get on with things, – for she had a house, a son and a husband to look after. Married life had not been easy for June; rather something she had put up with for fourteen years. She described her husband as bad tempered and a drinker. The tension within her marriage had caused her to worry and June

said she was frightened most of the time, reporting: *"he* [husband] *put me in hospital"*; a situation which followed a violent domestic incident, after which she divorced him.

June and her son continued to live together until he was eighteen and left home to join the army. On reflection, June said she had a strong relationship with her son at that time. He had always been good to her and she reported her blackouts didn't seem to bother him. In return she had always been there for him – "(…)*he always knew his meals would be ready and his clothes washed and ironed on time*". June's son used to return home during his periods of leave but shortly after he married June reported his visits home as less frequent and at the time of our encounters June no longer saw her son or her four grandchildren. Sending the children a birthday card was the only contact she had with family. June said this situation had arisen because her daughter-in-law had been "*a bit funny*" about her epilepsy.

June explained that after her divorce and bringing up her son it had taken a long time to get used to living alone but now that she had, she preferred *"the quiet life"*; a life in which she said she was a lot happier. Now, according to June, she *"doesn't take as many blackouts",* and attributed this reduction in symptoms to her changed lifestyle. She reads a lot; being by herself meant she didn't worry as much for she didn't have a lot to worry about. In claiming this time for herself June recounted experiences, that portrayed her efforts to cope with the worry of *"being epileptic"* - both in relation to her roles of wife and mother, as well as in other social situations. A recurrent refrain throughout these stories was June's perception that her symptoms created potential embarrassment for others: *"I feel as though I should keep away from people. I feel an embarrassment to people".* The depth of June's attachment to this view she had of herself had led her to withdraw from social situations, to shrink the world in which she participated and to routinise her daily accomplishments to better enable her to cope.

4.3. Chapter summary

The often chronic nature of epilepsy demands that individuals with the condition must manage their illness over long periods of time; thus it is important to study how they experience and cope with epilepsy within their biography or life-course. Biography in the words of Corbin and Strauss relates to:

> *"life stretching over a number of years and life evolving around a continual stream of experiences that result in a unique – if socially constructed identity"* (Corbin & Strauss, 1988, p.50).

The following chapters tell how epilepsy impacts on the daily lives of the 14 adults introduced above; how they give meaning to their illness experience, including how they talk about epilepsy; how their epilepsy is linked to broader social constructions and expectations, and institutions (for example, health and social care); and, not least how, in the face of a potentially stigmatising condition, they attempt to repair disruption and restore identity.

The next chapter follows the dominant plot emerging across the stories told by my participants. Their collective journey begins with the process of discovery, followed by searching for a cause, negotiating risk and uncertainty and striving for control.

CHAPTER FIVE

5. Agreement out of difference: a dominant plot across life with epilepsy narratives

5.1. Introduction

Participants, directed by my opening narrative question: *"Tell me the story of your epilepsy from the moment you realised or were told that something was wrong, even if those events were not formally defined as epilepsy*", saw 'onset' as a natural opening for their narrative account. This point of entry fits with the dominant orientation that stories have a beginning, middle and an end (Riessman, 1993). A plot confers order, sequence and meaning to a collection of otherwise isolated happenings. Events are defined not in terms of their singularity, but as the combined contribution they make to the unfolding of the story (Becker, 1999). In the current study, the dominant plot to emerge across collective stories told by my participants was one of a life disrupted, followed by efforts to restore that life to normal. Contributory elements in this dominant plot or story line included:

- *The process of discovery*
- *Searching for a cause*
- *Negotiating risk and uncertainty*
- *Striving for control*

Of course at an individual level no one plot or story line can adequately explain the complexity or ambiguities of a person's life; each life can only be understood through a multiplicity of stories. In light of this I use the expression 'dominant plot'. The dominant plot refers here to a context for shared experience; and as such has the "*capacity to model experience*" (Becker, 1999, p27) by guiding the way in which the events of my participants' lives, their opinions and their actions were interpreted.

In the construction and narrating of stories, a person must choose from a large stock of experiences and in so doing disregard some while incorporating others that they see as bearing relevance. How this dominant plot is interrupted and personalised, mediated by time, individual understanding and contingencies of circumstance will be explored further in chapters six and seven. However, my purpose here is to explore the turning points and

narrative elements of this dominant plot - comprising collective, meaningful stories of diagnosis, seizure events and treatment, symptom management, risk and loss of control, disclosure and stigma and stories of personal integrity – as expressions of disruptive experience. In so doing I shall examine similarities and differences in narrative elements across my participants as well as in relation to other chronic illness narratives.

5.2. Collective stories and narrative elements

Collectively my participants told stories that began with the process of discovery; however, I noted two distinctly different types of discovery stories emerged within their narratives. The first and predominant discovery story described the teller as having no prior signs of trouble; where the sudden onset of a seizure had been the first indication of something wrong and where, as a result of this occurrence, medical intervention was either sought by or, more often than not, enforced upon individuals as a result of the concerns and actions of others. The second type of story was one of seeking medical advice after experiencing warning signs of something not being quite right. For some this preamble to events began many years prior to the first medical consultation, while for others it referred only to those events that immediately influenced their decision to seek medical advice.

For several of my participants the moment of diagnosis presented itself as a relatively benign experience – questions about the meaning of epilepsy only became apparent as post-diagnostic life was lived; however for others the moment of diagnosis represented a significant turning point. 'Relief' at the point of diagnosis (Asbring & Narvanen, 2002) was not a predominant theme in the stories of my participants; rather diagnosis brought with it uncertainty about the cause of the condition, about treatment and seizure management, about the effects of epilepsy on lifestyle and coping and about the future.

Treatment procedures nearly always led to my participants experiencing side effects and often led to other social and medical complications. After treatment commenced, participants described themselves as still variously affected by epilepsy. They told stories of their quest to try and make sense of it all following diagnosis. They often drew on the knowledge of medical professionals, family and friends and other information networks in their search for answers and attributed new levels of significance to the roles played by both medical professionals and significant others in their search for social support and acceptance.

5.2.1. The process of discovery

5.2.1.1. No hint of anything until

A sizable group of participants (nine in all) reported no signs prior to the first documented seizure that might indicate that they had epilepsy. In fact the sudden onset of a seizure marked both the first hint of trouble and the diagnosis.

Karen recounted the first hint of trouble - the transition from a state of independence to a state of helplessness - with amazing detail. She described an evening out with friends at the squash club during which she experienced her first seizure:

> *"(…)and I was watching a few of the matches that were going on and I thought, mmm, there's something going on in my head. I couldn't envisage what it was. Then there's a…can't quite remember what it was…it was like a silence…with me trying to talk and a few people saying 'Are you all right? Are you all right?' And err, I was just shaking my head and err, feeling…I had always felt independent so thinking to myself no I'm OK, I'm OK, but don't know what the hell it is because hadn't been drinking, or anything…so erm, and next thing I said, 'going outside', and one of the girls said 'to get some fresh air?' So one of the girls escorted me outside and I went outside, it was dark, sat down on the tarmac and…still felt sooo… dizzy, it was…and then something happened, don't know what it was, I wasn't around, I wasn't there. And then, the next thing [sighs] I remember is lying on a bed going past the big bar area and then I… don't know what the rest was; Woke up the next day in the hospital".*

Karen's recall of time, place, and the physical sensations involved suggested that this event remained lodged in her memory and continued to mark a turning-point experience for her.

Other participants in this group reported having no memory of the events that precipitated their seizure. For Charles and June a sudden transition in their health status was recognised when they *"came round"* in the presence of ambulance personnel. For Charles, Stuart, Ricky, William, Fran and Jessica this transition was also marked by recall of the post-seizure reaction of family, friends and work colleagues:

> *"Err…I didn't know it was an epileptic fit or anything until I started to speak to the lad who was in the van with me and he said I started shaking and sort of convulsing…I was driving at the time and sort of came round in the back of an ambulance. But obviously I didn't know what had happened, didn't know it was a fit, didn't know what happened because I don't remember anything. I wasn't aware that I was sort of epileptic or anything".* (William).

> *"I was in erm…in a mess* [naval barracks] *of three and I was told by a couple of the lads that I was you know, having seizures at night. One of them [seizure] must have*

been a really bad one. One of the lads called an ambulance and then it was diagnosed". (Charles).

However, the visibility of seizures to others which remain unseen to the self often exacerbated the difficulty these participants experienced in accepting the condition:

> *"(…)well they say epilepsy, if you have an epileptic fit it's like a four hour workout at the gym because your body sort of constricts and does the sort of shakes and what have you. Erm, but I don't really remember anything of that. Like I say it's going off what people have said erm, and all I remember is going to the doctors coz mum and dad were concerned…I remember, you know, I didn't even know why I was going to the doctors in effect. It was mum and dad that were more concerned. My mum was like 'you've got to go to the doctors' erm and err, looking back, I remember me mum and dad talking about it and it's just a case of 'you've got to go to the doctors'. And I think my mum was worried that it might be some sort of erm, brain tumour or something like that, epilepsy wasn't a first thought".* (Jessica).

> *"They say apparently you use all the muscles in your body, so they say it's like running a marathon or something and you're using all the muscles so I was worn out basically like so I can't really remember. Came round, wasn't quite aware of what had happened, very sort of you know, disorientated and confused".* (William).

Martin's story of discovery marked a noteworthy exception to other sudden seizure onset stories, in that it did not pin point a significant transition in health status for him personally; though it did diagnostically:

> *"Eh, the last time I was in hospital I had a fit, or so they told me I had a fit, quite a bad one apparently, and err, that's what was decided, not decided but it was medically explained to me that I had epilepsy and that's when it came about their diagnosis".*

Martin learned of his condition during a period of hospitalisation for an illness he was dealing with prior to his diagnosis of epilepsy; an illness which required dealing with the physical and emotional challenges of rehabilitation. It is perhaps for this reason he experienced no significant changes in his health perceptions as a direct consequence of his first seizure occurrence.

5.2.1.2. Warning signs of something not being quite right

Participants in this group (five in all) told stories around unexplained symptoms, which subsequently led them to seek medical advice. Here Alan speaks of the physical sensations he experienced:

> *"I was about thirteen or fourteen; just starting high school. I think a couple of times I went a bit pale but my arm started shaking quite a lot and that's the only obvious*

thing and me breathing quite heavily sometimes. But that's the only thing; I wasn't foaming from the mouth or anything, that was it really".

Alan went on to explain how his symptoms increased in frequency and changed over time which led him and his family to seek medical advice and to learn of his condition:

"I started to have these attacks...On a good day I would say five to ten. On a bad day I would say ten to twenty; tops…I didn't really know what they were and we went to the doctors…like my heart started racing and I started shaking quite a lot and feeling, feeling quite woozy and that was it really. But it only lasted for about five, ten minutes. And then we went to the doctors, he thought it was epilepsy, but he wasn't 100% sure so he sent us to the hospital and they told me that I had epilepsy".

Larry recalled his early childhood warning signs as *"shivering and all that sort of thing";* his brothers would walk him through to his parent's bedroom when he *"woke up dizzy".* As a child, Ashley *"just used to go blank".* Brenda recalled the *"blackouts"* she experienced at school and reflected that on more than one occasion, *"I just wet myself";* these persistent, albeit intermittent occurrences ultimately led both Ashley and Brenda to learn of their condition. Yolande, while acknowledging her experience of unexplained occurrences from the age of fifteen years, chose not to disclose these experiences to others:

"Now I always thought to myself, there is something wrong here, how did I get to be here? I never said anything to anybody, but I've always remembered thinking there is something wrong here because I just don't remember".

It was several years later before Yolande sought medical advice following an incident during work as a junior school teacher:

"(…)apparently I had keeled over and knocked myself out, had a dent right on the front of my head from one of the desks as I fell, and err, I didn't know what had happened or anything…erm, I was off work for a couple of weeks, and then erm, the doctor at the time, erm put me on Valium for depression".

Yolande continued:

"I remember that about Valium [sigh] *…I don't need Valium. I don't need Valium. I'm not depressed* [laughs] *it wasn't anything like…So I carried on you know, I didn't bother with the Valium, and then the next thing I knew was* [husband] *said, you've got epilepsy because apparently I'd had an epileptic fit and of course he knew about epilepsy with his mother".*

As a consequence of her first husband's observation, Yolande returned once more to the hospital to undergo a series of tests and a brain scan; the outcome of which led to her formal diagnosis as having epilepsy at the age of twenty-five or twenty-six years.

5.2.1.3. The significance of 'moment of diagnosis' as a narrative turning point

Although a diagnosis of epilepsy served as formal confirmation of a change in health status, few participants described the moment of diagnosis as a significant turning point. Those who did recognised the immediacy of change to their lifestyle, made worse by the uncertainty and disruption associated with their post-diagnostic state.

Charles was one of the few who, upon hearing the diagnosis, admitted *"I mean it really upset me. I was cut up about it...knew I would have to be disabled through the Royal Navy".* Charles's diagnosis of epilepsy simultaneously meant his medical discharge from the Royal Navy. He immediately felt uncertain about his future, articulating:

> *"You're just shattered aren't you! I mean I joined there* [Royal Navy] *because it was something that I wanted to do and just to get the diagnosis the result that you were going to be disabled from the service all in one, one day, its just, it was just* [pause] *what can you say? You just don't know what to do".*

Like Charles, William's immediate concern was work related and centred on his inability to drive and the impact the loss of his licence would have on his job as a Royal Mail delivery driver:

> *"(…)when he* [consultant] *said you're going to have to tell the DVLA* [pause], *I realised I was going to lose me licence for twelve months and I couldn't do me normal job in work, that bothered me more".*

Alan was *"confused and worried", his* concerns centring on fears of how others might perceive him; thus his diagnostic encounter raised more questions for him than it answered:

> *"I didn't know what it…how it was going to affect my life. And affect my friendships with other people. But I was confused because I didn't know what it was and I didn't know what was going to happen to me over the years and I didn't want other people to see me as a freak of some kind, coz I've got epilepsy".*

For Jessica, the framework for her experience of diagnosis was uncertainty related to *'the problems with medication'.* She began her story in a way that captures the immediacy of the experience, by elaborating on the exact type of epilepsy she had:

> *"(…)it was a case of 'Right, its epilepsy, juvenile myoclonic epilepsy'…erm, you know. 'Most people grow out of it, you've been diagnosed with it now, and you'll probably be on medication for the rest of your life. There you go, that's it, that's the medication…' and that's pretty much it. I mean, I don't even…looking back I was so not even aware of what was going on. I think it was, and I was put on medication but*

no one went through the side effects of the medication, no one went through, you know, how to sort of manage it".

Jessica's comments regarding her diagnosis and treatment were, in effect, framed through the gaze of the expert. She adopted the voice of her consultant -*''Right you have epilepsy and need to take this medication…it will be for the rest of your life"* - and in so doing expressed a narrative of medical control. However, Jessica's reflexive comments - *"no one went through the side effects of the medication, no one went through, you know how to sort of manage it"* - serve to highlight how this medical construction of epilepsy failed to take account of the personal significance of her illness and did not allow her to construct a satisfying story to explain her experience: *"There was nothing about living, or if you need to speak to anybody; no support, sort of family-wise. It was pretty much there's the diagnosis".* A question not asked by Jessica at the consultation at which she received the diagnosis, but one that remained unanswered for her was – how was she to manage the uncertainty of her altered situation in everyday life?

In contrast, many stories told by my participants revealed that for the majority, questions of the meaning of epilepsy and how one might ride such disruption only became apparent when they re-situated themselves in the outside world. Thus, turning points occurred variously in the process of sense-making, as uncertainty and the experiential realities of epilepsy unfolded. My participants' portrayal of these stories as biographical disruption will be attended to in greater depth throughout the following chapter; here however, by way of example, Brenda's critical reflection on the occasion of her second seizure, five years post-diagnosis, aptly demonstrates the concept of a threatened biography (Corbin & Strauss, 1987):

"I started with epilepsy when I was seventeen. I was doing a pre-nursing course, and err, started with like err…petit mals while I was at college. I know, I can remember err, coming home and…to the bus stop and actually wetting myself, and err…it was just hard to accept and then, well just carried on and I don't know, I can't remember how I properly accepted it, I didn't really. And the tutor at college said 'Oh, you won't be able to do nursing'. Erm, I don't know whether it was because it wasn't controlled and diagnosed properly, or because I was actually epileptic, I don't know but erm…when I was twelve and I remember this as well, I was at the juniors having blackouts then. And I remember, I'll never forget, I was in class and I just wet meself and I just sat at the desk. I was off school for quite a while, but it only lasted about seven weeks err, because the doctor put me tablets…erm, but I didn't realise till I was seventeen that's what it was at twelve, if you know what I mean? Seven weeks after or so it stopped, and so from being twelve to seventeen I was fine through secondary school… So, but when I started at seventeen I finished the college. I went to work in a

factory with me friends mum, err, she got me a job there, coz I thought well nursing that's…over, I can't do that".

Although Brenda's story contains a number of elements around the question of onset and treatment, her story of diagnosis was not situated solely within a medical discourse; rather she drew on her social situation into which her epilepsy brought difficulty and disruption. Brenda's recall of time and place enabled her to link the two symptomatic seizure events at the age of twelve and seventeen years. Although acknowledging her epilepsy began five years earlier it is Brenda's elaboration of the physical sensations and her emotional reactions at the age of seventeen which define the situation; the sense of sudden disruption she felt at that time. Not only is this major life change experienced through bodily disruption (loss of bodily control through the occurrence of petit mal seizures and public display of urinary incontinence) it is also experienced as disruption to self and to the taken-for-granted future Brenda had imagined for herself, in terms of both her education and her career as a nurse:

"The thing was I just told the one particular tutor so I don't think it was looked into beyond her. She said you won't be able to do nursing with that [epilepsy] *so I just presumed because I had epilepsy I won't be able to do me nursing. I always regret really I didn't take it any further but it was just something that I thought, that they got, you know they got it right".*

Consequently, Brenda took the decision to leave college for as she said: "*I thought well, nursing that's over. I can't do that".*

5.2.1.4. The medical jargon of epilepsy

The occasion of diagnosis provided my participants with a definite descriptor of their condition. Some participants introduced personal perceptions of the medical history of their epilepsy, which appeared to enable them to integrate these medical terms into their own physical experiences. For example, Ashley explained how her epilepsy "*got twice as bad when she got older"* and "*went from petit mal to grand mal".* Fran spoke of her epilepsy being *"idiopathic"* and of having:

"(…)a mycloma [type of seizure] *before I actually go into a fit. I mean, I don't think I've ever not. It's a jerk, my arms will jerk…and I'll know then I've got to go back to bed until I feel OK or I think I can get up and do something and it doesn't happen. And normally, as I say, by mid-morning or early afternoon I'm fine".*

Charles explained that, *"nocturnal epilepsy was only sleep epilepsy",* which made it difficult for him to reconcile the loss of his career over something that only happened to him in his sleep.

Stuart described symptoms of his daytime "*petit mal*":

> *"(…)the ones I had in the day were like dizzy episodes, very petit mal…you stand there and you loose all awareness of what's around ya, and if you held a cup you'd drop it like and I've smashed some cups"!*

Karen described the benefit of *"an aura"* in affording her time to withdraw socially and prepare for her seizure event:

> *"I was still having an aura, thank goodness just before the fits started I heard music. So I had about half an hour warning from the aura to disappear. Erm…because I thought, whoops a daisy, especially in work, I thought, oh no, here we go. So I just went into the ladies toilet, locked the door which I did a few times…"*

This use of medical jargon, together with accurate descriptions of symptoms suggests, on the one hand, an objective medical approach to meaning making among my participants. However, there is evidence also in the accounts of these and other participants of actual or implied discomfort with the terms associated with 'epilepsy'. For example, following surgical intervention for the treatment of their epilepsy, Alan's *"anxiety attacks"* and Ashley's *"little feelings"* offer descriptors chosen to avoid the label of epilepsy. The sense that using a different descriptor somehow rendered the condition as less threatening was articulated by Alan, *"These anxiety attacks are nothing to be honest…anxiety attacks are weak; epilepsy is strong".* Similarly other participants, although not overtly expressing their discomfort with the term epilepsy, spoke of *"taking a black out",* having a *"fit", "dizzy spells", "not feeling so good", "drifting away"* or *"go in a daze"* – suggesting reluctance to use the language of epilepsy and seizures.

Some participants, while using the term themselves, expressed concern about the label of *"epilepsy"* or *"epileptic"* as a descriptor for their condition; concern embedded in fear and awkwardness about how others might perceive then them. Stuart and Yolande even likened the term epilepsy to the plague. Stuart noted that:

> *"Years ago it* [epilepsy] *was portrayed as if it were the plague or something".*

While Yolande applied this sentiment to her present day circumstance:

> *"It's like unclean isn't it, you know, you've got the plague, the mange or something; you know"?*

Similarly, Jessica noted:

> *"(…)epilepsy was this, like voodoo dolls and Africa…in some cases, Jesus Christ you'd had it if you had epilepsy! Bloody witches and all sorts!"*

My participants' discomfort with the term, epilepsy, echoes the expressions of stigma associated with the label of 'cancer', as described by Sontag (1990), where even the mention of the word cancer was seen to inspire fear. My participants were also aware that the label 'epilepsy' carried the stigma of social restriction. They used adjectives such as *"schizo", "freak", "weirdo", "mad", "deranged", "druggy", "drunk*" or *"skiver"*, to express their uncertainty and fear about how their social identity might be viewed by others as a result of the diagnosis of epilepsy.

Similarities were apparent between my findings and those from an early study conducted by Arnston and Drodge (1987). In their analysis of narratives that unfolded during a support group of people with epilepsy, these authors noted how participants viewed such social restrictions as the result of interactions; namely, the ways in which they were acted upon by others. Similarly, Schneider and Conrad (1980) noted that over and over in their interviews of people with epilepsy, participants spoke of a lack of understanding and knowledge of 'what epilepsy is' and this was perceived as a fundamental source of actual or potential negative reactions. Furthermore, Schneider and Conrad (1980) argued that what little information others held about epilepsy was probably *"incorrect and stereotypical; sometimes incorporating elements of madness and evil"* (p35). My own participants' comments suggest the label of epilepsy still carries powerful negative connotations - not only itself but as a consequence of association labelling - that when applied to an individual can, in Goffman's (1963) terms, 'spoil' their identity.

5.2.1.5. Just part of life's rich tapestry

The significance of epilepsy, however, sometimes receded in relation to particularly testing times in the biographies of participants – a point to which I shall return to in Chapter Six. For Larry and Yolande in particular, epilepsy appeared to generate less anxiety because of their life histories. Having dealt with difficult personal circumstances throughout her life Yolande spoke of epilepsy as being "*Just part of life's rich tapestry".* Speaking about a recent decline in her husband's mental health, Yolande said, *"I worry more about him*

[husband] *than I do about myself"* and "*he's the most important one really".* Larry, among other things, had coped with a *"horrible marriage"* and an *"alcoholic wife"*. He recounted selling the family home after his wife's death, to pay off his son's credit card debt; and how his attempts to be a good husband and father had been undermined. For Yolande and Larry such experiences represented a source of perspective for responding to and coping with the challenge of having epilepsy.

5.2.2. Searching for a cause

For several participants, the diagnosis of epilepsy prompted the need to search for a rational explanation for what had happened and why. Finding a cause, as Hyden (1995) suggests, may have provided them with a platform from which to develop and maintain a sense of continuity and meaning within the world. Many stories - some rendered invalid, others reinforced by medical professionals - revealed connections participants made between accidents that had befallen them or particular life-stage circumstances. Other stories portrayed a moral perspective as participants considered whether they were in some way to blame for their diagnosis or the severity of their epilepsy. Again, the attempt to identify a cause and to attribute meaning may have been beneficial, for as Williams (1984) asserts, this can assist individuals to develop a narrative that flows across time and as such enables them to *'reconstruct a sense of order from the fragmentation'* (p177).

5.2.2.1. Philosophical questions of 'why me'

In searching for the meaning of events, answers to the question '*why me'* were underpinned by participants' presumptions about the causes of epilepsy. As Brenda explained:

> "M*e Mum's always been convinced that it was when I was four; I had a road accident and I was concussed. She's always convinced that had something to do with it".*

In an attempt to seek affirmation for this belief, Brenda spoke of how she had *"mentioned this over and over to the doctors".* According to Brenda, while her mother was adamant about the cause of her epilepsy, she herself remained sceptical, acknowledging *"of course you can never prove that".* Similarly Ashley explained she thought originally her epilepsy was the consequence of *"a bang on the head"* when *"very young".* Latterly however, she learned from her consultant - following testing prior to resective surgery for the treatment of her epilepsy, that – *"Apparently, it was the convulsions that actually caused them,*

caused me to have epilepsy". This explanation of cause prompted remembrance of a key historical familial event, which in turn shaped Ashley's understanding of her diagnosis; *"me sister, she would have been forty-six now…err she died of them* [febrile convulsion]*".*

Some participants considered their predisposition to epilepsy in terms of familial transmission:

> *"I mean my dad had epilepsy when he was a boy but he'd grown out of it erm, and I often think maybe I would have grown out of it if they hadn't put me on that* [medication], *because I now think that I'm addicted to that, you know that medicine, that's how I feel. And I often think, 'I wonder why?' But then the type of epilepsy I've got, and it's hard because you think there's no reason, you know they say its idiopathic they don't know why, you know, I've got it and you think 'What causes it? Why? Why me?' I mean I've got four brothers and they are all fine, it's strange isn't it"?* (Fran).

Likewise, Jessica expressed frustration because:

> *"(…)no one would give me an answer to that, no one knows why people get epilepsy"…I mean, I started to go through the sort of, well why me stage…'why me?' And 'what is it?' and then came sort of like 'well why do people get it"?*

In searching for answers to these questions, Jessica's proactive attempts to educate herself about epilepsy led only to further frustration and to the realisation that her stock of knowledge as a resource for constructing a 'coherent story' of diagnosis, failed to account for her own situation:

> *"There's certain things that may trigger it, there's certain ages that you may get it…people can inherit it, erm, you know traumatic births can lead to epilepsy later…it was frustrating that I had it and it made me different in the sense that I had this label but didn't know anything about it and when they were sort of saying about inheriting some stuff it was like, we went through, or mum sort of went back and what have you and I think something like my granddad's cousin had epilepsy, so there was no like direct link…"*

The tendency in participants' stories to refer to discrepancies between their own experiences of the condition and medical explanations was apparent in the accounts of Karen and William. Both had been informed by their consultant that they had suffered from epilepsy since birth and both described bewilderment on hearing such an explanation. However, differences in the subjective representation of epilepsy come to light in their differing responses. According to William, *"(…)the consultant said it looks as though I've been born with something that should have come out when I was a teenager".* William,

unsure about why the condition should have started in his teens was nevertheless pleased that *"somehow it missed me"* at that stage and went on to explain*:*

> *"(…)it doesn't mean there was anything wrong to the brain itself. I was quite happy with that. There was no damage, injury or sort of bang or anything so there was nothing, there was nothing there that sort of suggested I was going to have more. Because of that I wasn't really, I wasn't really too concerned".*

William not only found the consultant's explanation acceptable - *"I was quite satisfied with his answer"* – but, as he went on to explain, it was also an explanation that coincided with his own perception:

> *"I was just finding out things about it and there were things that reassured me saying like if you have a fit you are more likely, the chances of you having another one in the next six months are quite high. And alright I have had two in the six months fair enough, but I have also learnt that 50% of people, who have a fit, never have another one. So that's sort of, that reassured me".*

Karen however was unable to rationalise this medical theory of susceptibility when put forward by her consultant and rejected it out of hand, articulating:

> *"(…)he* [consultant] *was looking at an X-ray which was two years old and he said 'You've had epilepsy since you were born, definitely since you were born.' I said 'What? No.' I said".*

Her consultant's explanation did not make sense in relation to her experience; *"how come it hadn't been spotted beforehand".* Karen's need to link cause and effect led to her generating her own theory which she expressed in a *'flu jab'* story. Karen tells of how in preparation for her move to London to begin a new job, she received a flu injection; and three weeks later she experienced her first seizure. Karen remained convinced that; *"I had it [epilepsy] after the flu injection".* Such critical reflections on personal characteristics and family health history echo sentiments expressed in many participants' accounts of their attempts to make sense of such a diagnosis; especially, as is the case in a significant percentage of cases, when the cause of epilepsy could not be medically identified.

5.2.2.2. Pinpointing cause and effect

Karen's flu jab story demonstrates how participants, in search of a coherent interpretation of their experience, also told stories in which they implicated serious events or other emotional upset in the emergence and onset of epilepsy. As a further example, Martin

believed his epilepsy stemmed from the emotional shock of his friend's death, whilst serving in the armed forces:

> *"That's when it affected me. Yeah, over me radio, I was in the army at the time. It was a very close friend of mine and he was shot, killed outright".*

Martin reported enduring prolonged stress as a consequence of army life and said even after his discharge he continued to experience *"recalls of things that happened*" which he believed "*may have something to do with the epilepsy".*

The utility of the concept of stress in the emergence of epilepsy was also evident in accounts from June and Fran. June considered the onset of her epilepsy as the possible outcome of being administered anaesthetic gas during the birth of her son – though her consultant's analogy that the brain was like a plug - *"if you over load a plug it will blow a fuse and he* [consultant] *said, well that's what you're doing…blowing a fuse until it calms down"* – was also an explanation that held resonance with her. According to June, she was under a great deal of pressure at the time because *"me marriage wasn't very happy. I didn't have a happy marriage and erm, that made me feel erm, bad. You know I was always worrying about that".*

Similarly Fran, unable to fully attribute family history to the cause of her epilepsy - her father had *"grown out of it* [epilepsy]*"* and her four brothers "*were all fine"* –, also considered the impact of lifestyle stresses. Following a long period of seizure remission Fran recalls, *"It just started happening and I had three or four fits in the space of eighteen months".* Describing the time leading up to the recurrence of her seizures Fran noted that she had relocated to the south of England, was living in a new home with her partner and had started a new job. Fran's notion of stress - the consequence of such lifestyle change – as a precursor to seizure reoccurrence was subsequently reinforced by medical professionals. As Fran put it:

> *"I went to the Infirmary and they said, 'You know, I think it's just a change in lifestyle, stress can often affect epilepsy' and that's just what happened and they did an EEG and nothing had changed so it was just sort of that…I came back up here* [home town] *and things settled down really".*

In considering the nature of epilepsy, women participants of child bearing age - Ashley, Brenda, Fran, Jessica and Karen - all told stories that revealed their perception of a causal connection between menstruation and / or pregnancy and seizure occurrence; a

connection not legitimised in their clinical encounters with medical professionals. The following comments echo the sentiments of my women participants:

> *"(…)it* [epilepsy] *got worse as I got older from like menstrual problems. It was on the menstrual side coz ten to fourteen days before a menstrual cycle I used to have more and more* [seizures]*".* (Ashley).

> *"I mean it seems to be sort of the week before my period is due that I know this will happen to me so I just started keeping a diary of it you know? I was saying to* [consultant] *I've been keeping a diary for when it* [seizure] *happens and it seems to be linked to my menstrual cycle as well, which he didn't seem to, he didn't comment on at all to be honest, but I do feel that. So, maybe as I become menopausal or pre-menopausal maybe it will change again, I don't know".* (Fran).

> *"I'd have warnings two weeks before I was due on and sometimes as well the week I was due on, so everything around the period stage for about 2 years and maybe a bit more. And then I was due on and I'm thinking that's 4 days and 2 days and I'm thinking I should have had a fit by now. And so from September, all the way through for about 6 months didn't have a period and didn't have a fit".* (Karen).

In a continued search for sense-making, where personal characteristics and family health histories failed to deliver a plausible explanation for their condition, some participants also wondered about their own behaviour. Attributing his lifestyle and behaviours as a potential cause of his *"fitting"* Martin explained that in face of continued emotional distress he had turned to alcohol. He considered his previous social behaviour as a potential precipitant of his seizures, articulating:

> *"(…)plus I started drinking heavily after* [friend's death], *the epilepsy may have been to do with the drink, not the epilepsy to do with the drink, but me fitting to do with the drink and my drinking".*

Brenda expressed similar concerns:

> *"I mean I did used to have a drink, we used have a good night and sometimes that might not have helped. It probably didn't. People say now, 'oh you're very brave and you get on with it' but if I'd carried on the way I were when I was 20, in me late 20's, then I always wonder what would I have changed into; an alcoholic or something"?*

She continued:

> *"Sometimes I wonder, was it going out having a good time that made the epilepsy, not worse, well it is worse coz it's not controlled but would I have been any better"?*

In interpreting and drawing meaning from this experience, Brenda wondered whether, had she continued with her earlier lifestyle, she *"could be dead by now".* However, I came to learn from Brenda's story that it was not being diagnosed with epilepsy that acted as a

stabilising influence on her lifestyle; the turning point came with pregnancy and the birth of her son:

> *"I look back and think 'do I regret it?'* [her social behaviour and drinking habits]. *I don't, I don't regret it because we had a good time. Now it's the total opposite because I've me son to consider. Ever since I had him, I don't know where or what I'd be like to this day if it weren't for having my son".*

Brenda's comment, "*I've me son to consider",* aptly demonstrates Williams (1984) concept of 'narrative reconstruction' where disruption and suffering can be brought under some form of meaningful control. Here, for example, Brenda is able to re-interpret life events in light of her changed circumstance and relationship in the world in which she lives, "*I don't know where or what I'd be like to this day if it weren't for having my son".*

5.2.3. Negotiating risk and uncertainty

After receiving the diagnosis, participants were left confronting the emotional and practical problems it posed. In the process of responding to this knowledge and accounting for their condition and circumstances, the epilepsy plot line is played out in stories of risk and uncertainty. The settings and characters in the stories told by my participants vary across time and place as they faced the challenges and issues produced by epilepsy; reflecting the consequences of this condition across all domains of daily life. Negotiating risk and uncertainty meant that for some participants the knowledge that they had epilepsy often interfered with daily living, even in the absence of (intermittent) physical dysfunction. Epilepsy modified participants' participation in working and social lives, and relationships, as well as in relation to their sense of self.

5.2.3.1. The impact of healthcare encounters in relation to risk and uncertainty

While participants came to understand that epilepsy was a chronic condition requiring continuous engagement with healthcare professionals, they told stories that highlighted the impact of this engagement on their perception and interpretation of risk and uncertainty. Participants recounted stories reflecting, to a greater or lesser extent struggles with health professionals and the health service. Thus, notions of uncertainty and risk were not only entwined in stories of cause and diagnosis but also in stories of subsequent treatment and management and for some, the difficulties encountered in searching for treatment.

It needs to be acknowledged at this point that not all these stories positioned healthcare professionals as outsiders who "*don't understand*". This perspective was balanced in part with tellings of affirmation. Here, participants insightfully recognised good practice; telling stories which portrayed sentiments of trust and satisfaction when things had gone well and the acknowledgement that professionals had demonstrated caring and supportive behaviour. This is portrayed in Stuart's evaluation of the quality of the relationship he had with his consultant:

> *"He'll* [consultant] *always sit and listen. They will always put their point of view and then ask you, how you feel. I was in the position, with* [consultant] *where we could just phone up. If we didn't have an appointment, just phoned up when we wanted to see him, and he would give us an appointment that week. You know, we had that kind of relationship with him".*

However, often participants spoke about the negative attitudes of health professionals in relation to specific needs, the poor quality of care and treatment received and the ambiguity in information provision. Several said that prior to diagnosis they had perceived medical professionals as sources of information and as having the ability to provide adequate information. However, participants often spoke of experiencing both gaps and conflicts in the information and treatment advice they received, raising questions about who had expertise. Such issues remained key mediating factors in personal notions of uncertainty and risk.

Medical professionals featured as key characters in the narratives of Fran and Jessica in particular, both of whom told a number of stories related to their healthcare encounters. Fran, reflecting on events around her second pregnancy and her efforts to determine the safety of continuing to take her prescribed anti-epileptic medication, Sodium Valproate articulated, *"(…)to me there are so many mixed messages from the consultants themselves"*. She went on to explain:

> *"I was already pregnant and I found out it could have effects on, you know, the children could have learning difficulties. I'd never been told, about erm abnormalities, you know physical abnormalities, and it was always a horror going for the scan, that was always a nightmare".*

Fran continued:

> *"I think I was having a 20-week scan and I was saying, 'should I be on the Valproate when I'm having a baby?' he [doctor] said, 'Well everyone will tell you, each consultant will tell you something different, you should have maybe been on Lamotrogine…I remember a nurse saying to me 'If you were under this Mr whatever*

in Birmingham you would be on Lamotrogine, you wouldn't, under no circumstances would you be taking Valproate'. But here they let you because of your epilepsy, this is the best to manage it…get on with it kind of thing".

For Fran, the latent risks and uncertainty associated with her reproductive status were to become manifest several years later, when her second son was diagnosed with a learning disability - which she attributed to the side effects of her prescribed anti-epileptic medication:

"I was already pregnant when I found out it could have effects on, you know, and I've since found out that my middle little boy has mild learning difficulties, and that was just…[silence, Fran began to get upset and continued to talk whilst crying]*…this statement about there is now a worry that it can affect children erm…developmentally, and you know I was just hysterical, it's just that you want the best for your child".*

Fran articulated how the *"take this and get on with it"* attitude of her medical team had left her feeling that her condition had neither been considered nor understood in the context of her personal circumstances. This experience had raised considerable uncertainty for Fran, not only about whose medical advice to take, but also about how to judge the validity of the advice given.

Fran considered the perceived lack of consideration by healthcare professionals in relation to her "*specific needs*" as a point of frustration which became a continuous thread throughout her stories of daily routine:

"I do feel that because I'm not fitting during the day they [consultant] *just sort of, you know? They are not taking it seriously…Coz talking to consultants about it, with all the best will in the world, they're useless. God forgive me but they are useless".*

Fran explained, *"My whole life centres around worrying about getting up in the morning because of the boys, you know"?* Her husband's business required that he work away from home a lot of the time, leaving Fran with the responsibility of getting three young boys their breakfasts and off to school on most weekday mornings. Fran continued:

"I may wake-up having a Mycloma [type of seizure] *and have to go back to bed and that's it then; the whole day is out. I can't do anything until maybe mid-afternoon when I know I'm okay, coz I won't take the chance obviously because I've got three children with me".*

The occurrence of Fran's nocturnal and awakening seizures disturbed her sleep and made her very tired the following day; such tiredness according to Fran, affected her ability to care for her boys:

"(…)it's a big worry every night going to bed thinking am I going to be okay in the morning. It's always there in the back of my mind, am I going to be okay in the morning because of the children"?

Expressions of Fran's frustration in relation to her consultants' perceived lack of understanding continued:

"It's as if, you know, well you're not fitting every day so I don't know what the problem is. You know, that's how I feel. And, like, last time I went to see (consultant) he sent me to see a psychologist and I know he thinks I'm neurotic because of what's happening of a night-time".

Fran's medical encounters, where her own bodily experience was challenged by professional opinion, coupled with the lack of acknowledgement of the impact of her nocturnal seizures on daily functioning and routine, served only to heighten Fran's sense of vulnerability. Positioned by her consultant as over-anxious, Fran's perception, "*they* [consultant] *don't take seriously what I say",* only added to her perceived sense of risk, which for Fran threatened 'good mothering'.

Similarly, Jessica's *'*problems with medication' story, articulated earlier in this chapter, not only provided a significant narrative turning point but subsequently provided the framework for Jessica's post-diagnosis treatment stories. Stories of medication and treatment featured heavily in Jessica's accounts and served to highlight the risk and uncertainty she associated with her post-diagnostic state:

"And I remember when they gave the Epilim medication, what I've since found out is that Epilim is one of the high risk, as far as pregnancy and that stuff is concerned".

Jessica went on to explain that it was only through research she and her mother had undertaken via the internet that:

"(…)it came to light about the Epilim medication, about like pregnancy and the risk to pregnancy and the fact that it could have a lot of implications birth wise. It was one of the higher risk medications".

Jessica expressed concern about the lack of relevant information about Epilim from healthcare professionals and the significance of this omission in relation to her current identity as a woman of childbearing age and her envisioned future identity as a mother. She went on to explain:

> *"I felt really frustrated because they'd not told me about polycystic ovaries and things like this. And I remember that I had to then go through ultrasound and things like that, checking out whether I had polycystic ovaries, which thankfully, I didn't"*

Jessica also described how her consultant's suggestion that she continue with Epilim positioned him as *"lacking in understanding"* and support in relation to her own circumstances:

> *"It's all right for him because he was a bloke; he just didn't seem to have any understanding as to my concerns about storing up potential problems".*

According to Jessica taking Epilim was not an option, *"not if it's a high risk"* because *"it* [Epilim] *was just storing up problems"* for the future in relation to her ability to bear children. She felt isolated in her subsequent treatment decision making – having refused the consultant's suggestion to continue with Epilim she recounts how she was told:

> *"You've got these choices of drugs for the type of epilepsy you've got, go away and let me know which ones you want to do…".*

Fran and Jessica's stories of risk and uncertainty associated with their reproductive and maternal status illustrate the importance of women with epilepsy receiving specialist advice from healthcare professionals (Epilepsy Action, 2013). This advice should include information regarding contraception, pregnancy and family planning prior to the start of treatment and considerably before they get pregnant (Winterbottom 2012). Treatment options need to be discussed with patients in the context of individual need, as pregnant women taking anti-epileptic medicine have a higher risk of carrying a baby with developmental problems and malformations than other women (Meador et al., 2006; 2011; NHS Choices, 2013). In addition this risk increases if more than one anti-epileptic drug is being taken to control seizures (Morrow, et al., 2006). However, women with epilepsy also need to be advised that treatment withdrawal because they get pregnant may cause seizures that can, potentially, be more harmful to both mother and baby than continuing with their treatment. Explanation of these issues together with appropriate support to assist women with epilepsy in their decision making around treatment options will do much to alleviate pain and distress.

From the 'Epilim' story Jessica moved directly to another inter-related medication story. Here she told of the many side-effects of her subsequently prescribed medication; the meaning of which was heightened by the consultant's rejection of Jessica's lived expertise

about her bodily experiences and the ongoing struggle she faced in raising matters which were of concern to her:

> *"I was on walking sticks and I sat there and he said, 'So what's the problem?' And I just looked at him and thought, are you for real? You know what has gone on, you've seen me with walking sticks and I said to him well my legs completely off, back pain, I've got problems with the alignment of my hip, then again there's my arm…and he looked at me and went…his exact words were 'I'm not bothered about that, I'm bothered about the epilepsy'. Ironically the epilepsy was fine; the medication was causing the problems in my view… And I've since been on the internet finding out all sorts and a lot of the side effects of this medication were the side effects I described".*

It was as long as over 30 years ago that Schneider and Conrad (1983) argued that good quality epilepsy care required the adoption of a holistic rather than a biomedical approach, and an emphasis on the principle of co-participation in care. While we can argue there has been much progress over the intervening years in the pursuit of these goals, with evidence based guidelines for assessing, diagnosing and managing epilepsy (NICE, 2012), I would argue the challenge for health professionals lies in the fact that epilepsy, despite these efforts, still breaches what Werner and Malterud (2003, p1417) called, *"normative, biomedical expectations of what illness is and how it should be performed".* In that the often unexplained and chronic nature of epilepsy not only challenges the effectiveness of biomedical strategies, but participants' accounts also highlighted the struggle to make the psychosocial symptoms of their condition visible and real when consulting their doctor.

Jessica's story serves also to sensitise us to the disparity which continues to exist between cultural notions of how things ought to be and how they actually are. This situation is exemplified in her concluding remark:

> *"No one looked at the whole picture as to what was going on…and that person, supposedly the consultant, was supposed to be looking after me".*

An interesting counter story is one articulated by Brenda. While many of Brenda's stories contained graphic accounts of the frequency and severity of her seizures, the injuries she sustained as a consequence of her seizures, and her body's limited response to both medical and surgical treatment regimens yet somewhat surprising, medical professionals did not emerge as primary characters in her narrative. Despite that these stories served to vividly portray her bodily experience of epilepsy and her ongoing need for healthcare intervention, she only gave voice to her consultant (*"Oh, this is an unusual case"*), when she expressed uncertainty about the future she had envisioned for herself. This medical

validation of her condition carried significance for Brenda as it underpinned her own awareness of the uniqueness of her clinical situation and served to heighten her own interpretation of embodied sensations and of personal risk. Brenda's line of reasoning was that her condition could be more than epilepsy – that she *"could be going mad".* Brenda's perception of her vulnerability to mental illness becomes more understandable when we consider her story in context. As Brenda continued, the strength of her own interpretation was demonstrated by her narrative integration of her own bodily knowledge of ill health and her experiential knowledge of caring for patients with a mental illness:

> *"I'm convinced I'm going mad. I mean I see cases at work…It worries me because I think it could be early Alzheimer's. Sometimes, and with mine [*epilepsy*] it's yeah, in a way because it's brain cells; it's killing your brain cells, isn't it? Erm and we had this particular patient and I'm thinking I go like, I just go like that. We have a patient that had epilepsy and the* staff nurse *said to this social worker, she said well, sometimes with epilepsy it can go onto Alzheimer's...I know, I know it could do, quite easily, because we've had cases like that and the way that it's* [referring to own condition] *not being controlled I wonder is it all epilepsy? Is there something else going on up there? But I said to the staff nurse, I said, 'when do you know?' She said, 'well that's the frightening part, you don't ever know'. Erm, so you know, it does bother* me".

In constructing one possible future for herself, Brenda's sense of vulnerability to mental health issues is given narrative meaning through salient personal experience and the patients for whom she cared. I asked if Brenda had discussed these concerns with her medical team:

> *"Just briefly; I was thinking of having another scan, but I'm frightened to death of having another scan done really because they do show, it does show it up, coz we have patients that have scans done and it shows up where the Alzheimer's is. But with me it shows up where the epilepsy is, but whether they can define that it's Alzheimer's or not, I don't know but I'm frightened to death of them doing that".*

Here we can see how observations of personal risk, heightened by health professionals' comments and first-hand experience, caused Brenda to evaluate information and treatment. Observing their debilitated condition, others Brenda observed became a *"living symbol of who and what she herself could become"* (Charmaz, 1983, p174), clearly contributed to her sense of increasing vulnerability.

While Jessica and Fran's narratives position their consultant in a less favourable light than Brenda's narrative, all these stories suggest that the patients' own situated experiences are often in conflict with medical knowledge and scientific claims and that patients' whole stories are seldom heard. As noted by Latour (1987) (cited in Horton-Salway, 2004) this, in

part, arises because the 'expertise' of health professionals is situated within different social constructions of reality (within this study, medical constructions of epilepsy as discussed in Chapter Three) to those of the patients; and different networks are utilised to support medical claims. The patient needs the health professional to bring medical meaning to their symptoms and experiences and in so doing to bring a degree of structure (or certainty) to their world; a world often made chaotic by epilepsy. However, where health professionals are unable to bring this meaning and structure and where there is a lack of shared meaning within the medical encounter, confusion and uncertainty may arise.

Using these stories as markers for practice change, they serve also to demonstrate that much may be gained by encouraging patients to develop an extended account of their illness; one which includes as much as possible of the rich set of psychosocial circumstances in which their symptoms are embedded. Uncertainties that remain unacknowledged will likely remain unresolved, reflecting a clash of perspectives and increasing the potential for conflict (Bissell, et al., 2004). Werner and Malterud (2003) comment that:

> *"doctors find consultations with medical uncertainty, interpersonal difficulties, chronic and so-called unexplained disorders difficult to manage….They find it problematic to handle distrust, and to demonstrate their own shortcomings when carrying out medical consultations".* (Werner & Malterud, 2003, p1410).

While this proposal was drawn from research findings that focused primarily on women with chronic pain, these conclusions carry resonance for others with chronic and / or unexplained symptomology - as is potentially the case for some people with epilepsy. Frank (2004), calls for the 'renewal of generosity' by health professionals during their engagement with patients and a willingness to open themselves up to having opinions changed. Space for this needs to be calved out in the routinisation of care - technical accounts, medical charts and history taking are not a story, since they fail to address personal experience. By closing down the potential for 'meaningful' communication within the medical encounter, confusion and struggle between patients and health professionals will inevitably arise.

5.2.3.2. Negotiating risk and uncertainty associated with daily living

In addition to in the context of healthcare encounters, risk and uncertainty were embedded characteristics of living with epilepsy on a daily basis and had the potential to negatively impact on participants' functional and emotional wellbeing. The generic concern - will *I* have a seizure *today* and *where will I be* - was common among my participants. For

example, Alan worried constantly *"because I didn't know when they* [seizures] *were going to happen*" and Stuart explained, *"I didn't have any* [seizures] *for ages in work; then bang, bang they started".* There were times in the lives of my participants when the uncertainly and unpredictability of seizure occurrence placed them at considerable risk. As an example, Larry recounted one such experience that subsequently led to his early retirement:

> *"I was working up a right big height and I just dropped down. I was about 200 foot up scaffolding and they lifted me down in a crane and everything".*

June, while acknowledging she felt she had no option but *"to get on with things"*, recalled one of the dangers of *"suffering with blackouts":*

> *"I'd walk over the road in front of cars and buses and me mind 'ed blackout. I'd come round to find the drivers screaming at me; stupid bitch, why don't you look where you are going".*

Ashley told me: *"I'd be thinking Oh, will I, will I have one* [a seizure]; *what am I going to do"?* The disquiet she felt regarding her susceptibility to seizures meant that often Ashley preferred to remain within her home. She went on to explain:

> *"I was frightened to go anywhere*. *And that's what got me the way I am now; I'm insecure. I'm frightened to go out unless I've got someone with me, unless I know the place".*

This constant shadow of uncertainty around potential seizures and their consequences made it difficult for some participants to frame their lives positively and to remain optimistic. For Ricky in particular, the meaning of epilepsy was framed and articulated in negative connotations of what "*can't"* be done*:*

> *"You can't drive, you can't really cook, if you go out you are only allowed to have one or two pints a week. You can't get up ladders, and like when you get a bath you are supposed to really have someone supervising you to make sure you don't black out in the bath and drown yourself".*

Ricky noted how *"you feel worried"* about the ever-present risk of a potential seizure. He went on to explain:

> *"You can't have people with you 24/7 and I still got to take kids to school and cross roads and once they're in school, come back by yourself. You're just trusting to luck that you don't have one on the way home".*

Living with this risk on a daily basis meant that like Ashley, Ricky was often *"scared to go out"* or to do *"anything too dangerous"*, especially if his children were with him. Not wishing to put himself or others at risk, he believed his daily life to be *"restricted".*

Stuart too considered the potential risk of seizure occurrence on his daily activities and life style: "*I always have to have someone with me".* Stuart, an avid football fan, explained he had purchased an additional season ticket to enable someone to escort him to the matches and that he had restricted himself to walking the dog "*around the estate and not down by the canal*" in case he "*fell in*". Reflecting on the need to do *"the sensible thing",* Stuart explained that he had undertaken these measures as a means to managing both his own and his family's worries in relation to seizure risk.

Martin noted that after his release from the army, the risks associated with his epilepsy had placed a restriction on him applying for jobs in "*Civvy Street*" - jobs he considered he was otherwise experienced and fit enough to undertake. As an ex-army man, proud of his fitness levels, Martin's dream job had been to become an Outward Bound Instructor. However Martin chose not to apply for such positions. This was his way of protecting himself emotionally; there was risk to his self-esteem in terms of anticipated rejection: *"I know I would be rejected if I'd told them about the epilepsy".* In addition there were the risks associated with the need to *"maintain the safety of others".* As he explained:

> *"(…)this job involved taking others out on expeditions and climbing and hill walking but 'cos of the dangers to others* [because of the possibility of having a seizure] *I wouldn't do it".*

While the restriction that epilepsy had placed on Martin's employment opportunities was *"frustrating and upsetting"* he acknowledged that in certain circumstances it was morally justifiable: *"it's a restriction in these particular circumstances that I can understand".* Martin qualified his understanding by explaining that if he wanted to do something where the risk of having a seizure was a risk to him alone, then he would go ahead and do it; but not where having a seizure extended that risk beyond himself to those under his supervision. Martin's position was a moral one, in that risk to him was acceptable, but risk to others was not.

As discussed in the previous section of this chapter, one aspect of risk expressed by Brenda was her certainty that her condition might be more than epilepsy and that her future health

was at risk. There was also no denying that Brenda's physical health had been at considerable risk over the years as a consequence of her seizure events:

> *"I remember falling down stairs with Peter* [son] *when he was a baby and I'd had a seizure. I must have fallen back at the top of the stairs…I was carrying him. He wasn't hurt but I'd bruised me ribs".*

In fact, during our conversation, Brenda recounted a number of accidents that had impacted on her physical and emotional wellbeing. She continued by recounting the occasion she *"…spilt a cup of tea".* This incident resulted in her being admitted to hospital for as she explained: *"It was right in my groin; and it took the skin off".* Brenda had subsequently spent a further eight weeks in hospital when, following a seizure, she fell unconscious onto the open fire. Lifting her hair aside, she revealed the burns she had sustained to the left side of her face and said*, "You can see what happened; fingers amputated too".* It was not just the obvious physical risk to her health Brenda considered; she was also plagued by guilt over how her condition might also place her son's wellbeing and their relationship at risk. As she explained:

> *"He* [son] knew *that I'd had an accident, he didn't know how bad it was…he didn't come up and see me for a few days because I wasn't really in a fit state for him to see, it would have been a big shock to him. He had to cope with that and cope with going to school and I was in hospital for eight weeks and he come up to see me as regular as he could. But sometimes I have thought, does he hate me for being me and me with epilepsy? He probably doesn't, I don't know but that's what I think sometimes because it's not been straightforward. I mean I've not just had epilepsy, I've had serious burns to me face and to me hand and he's had to cope through that with me".*

Brenda expressed her desire to be a good mother, but she was cognisant that her health issues often interfered with her daily activities, leaving her unable to fulfil her parental responsibilities. She offered an example:

> *"He [son] stayed at me brothers and stayed with their family and was one of them and as long as he knew I was at the hospital and was okay he carried on as I wanted him to. I mean sometimes he's said 'wish you were dead'. I mean I don't know if all kids say that but sometimes I think does he hate me, does he hate me that much"?*

Similar to Martin, Brenda's comment calls attention not only to the potential risk of epilepsy on functional health, but how, for some, having to prepare oneself for the reactions of others carries even greater levels of anxiety and risk – the risk of potential rejection and stigma.

Alan too articulated his sense of rejection in terms of becoming *"an outsider".* According to Alan, *"I had to be careful about playing football just in case I got kicked in the head and I was always worried about getting hurt in the head".* Alan therefore, *"stopped going out as much"* to play football with his mates, with the result that *"Basically they forgot about me*". For Alan, this anticipated rejection or felt stigma (Scambler, 1989; Jacoby, 1994) was a powerful force circumscribing his social involvement, for according to Alan, the consequence of his friends' actions had led to him *"feeling like an outsider".*

The risk of rejection and enacted stigma from outsiders, friends and family was a fear also expressed by others. Brenda sadly recounted an appalling incident on the first occasion she collected her son from school following her discharge from the burns unit:

> *"(…)me hair was cropped, cut short, because it had to be because of the damage it had done and I went and picked him up and I was dreading it, absolutely dreading it. People did know the situation 'cos it's a close-knit community, erm…so I stood there in the playground with half me blooming face like err… phantom of the opera. Kids were looking, most of them knew what had happened, not saying little ones did but do you know the worst person, the worst thing was there was one of the mums was looking and I mean I knew people would look and I accepted that, so I moved and she moved, she moved to have another look at me and that's a fully grown woman. And I felt…*[pause] *well I were going to cry".*

This negative experience, albeit from an impersonal source, contributed to Brenda's reticence *"to get back out there".* Other participants recalled less flagrant instances of rejection and discrimination. However, it was not surprising to learn that discriminating comments and avoidance from friends and family members carried the greatest risk to participants' sense of self and their relationships. Even seemingly supportive others appeared, on occasion, to participate in hurtful behaviour. Fran for instance recalled an incident, in which her mother, with whom she had a close relationship when younger, commented about her epilepsy, *"you were lucky to get someone to take you on".* Fran was most hurt by the fact that her mother, a qualified health professional, appeared to rely on myths and stereotypes rather than informed knowledge to underpin her thinking:

> *"(…)it's the way people perceive it* [epilepsy] *and I know that mum thinks that; I know that she feels that way, that old fashioned sort of thing. I know she feels that way".*

Fran indicated that now, apart from her husband, she spoke very little about her epilepsy to others; not even close family and friends, as she felt they didn't really understand.

In her account of her experiences with epilepsy prior to her resective brain surgery, Ashley indicated that if her mother had been unable to help, she always called on her partner for practical assistance and support, which she received from him. However, over the years, Ashley reflected on how her partner's behaviour often contradicted his *"love"* and *"acceptance"* of her epilepsy status:

> *"(…)me partner, he doesn't speak about my illness. I used to say, you know, about seizures and he never even looked at me or cuddled me, you know?"*

Ashley's seizures diminished following her brain surgery. The physical improvement in her condition, together with personal efforts to re-gain control of her life subsequently lessened Ashley's fears of rejection*: "Because it's* [having a successful surgical outcome] *brought, it has brought us all a lot closer as a family".*

In summary then, risk, both actual and perceived, affected my participants' lives in various and disparate ways; their narratives consistently demonstrated their perceived vulnerability both to physical and emotional risk. Giddens (1979) spoke of illness as being representative of a 'critical event'. There is a theoretical argument here, I suggest, for extending the concept of 'critical event' beyond the singular, because the consequences of epilepsy and seizures represent 'multiple critical events' with the potential to disrupt individuals' lives repeatedly and present very real barriers to participation in working, family and social life.

5.2.4. Striving for control

As has been seen, the symptoms and associated problems of having epilepsy presented themselves as an ever-present challenge. However, a number of participants tried to regain a sense of control, as a means to re-organise everyday life and to better deal with an uncertain future.

5.2.4.1. It's that element of the unknown

Several participants spoke of a loss of awareness of self during seizures as one aspect of living with epilepsy - typically in relation to not knowing what happened to them during their seizure event(s). As Ricky explained, *"When I have one [seizure] I'm the only one who doesn't know like what happens".* Similarly, Fran noted that *"It's that element of the unknown, you know, you're gone".* She expressed how terrifying it was, "(…)*not knowing what's happening to you and not being in control of what's happening to you*". Stuart too

noted, *"You lose all awareness of what's around ya…you've got no power over them* [seizures], *you could be anywhere".*

Jessica stated, what for her, represented the experience of loss of control:

> *"(…)because your body takes that control out of your hand. You can't control what your body is doing, your body is doing it regardless, and you don't have any knowledge of what's gone on. People are telling you what's gone on. You don't know what happened and you can't piece anything together because you don't know anything about it; moments, minutes, however long it is out of your mind. And then you're sort of having to live with what people are telling you, accept that and like I say, it's just erm…out of your control".*

While Jessica did not have actual knowledge of what happened to her body during a seizure event, I asked her if she had any assumed knowledge or any preconceived ideas about what might be occurring during her seizure events. She replied: *"I think at first I just didn't give it a thought either way".* For Jessica the realisation of the extent of her loss-of-self came following a seizure event, when her father told her she had been, *"(…)foaming at the mouth".* As Jessica explained:

> *"I thought NO! But Dad had got no reason to lie. Erm…but it does sort of shock you I think. To then realise how out of control you are and it's your body".*

Karen spoke graphically about an event which she said, *"still puzzles me today".* Following a seizure which began by her kitchen sink she recalled:

> *"(…)waking up the opposite side of the room, stuck between the door way and the fridge freezer. I was in a cramped position. I thought well how did that happen? I just couldn't imagine how my body had moved from one side* [of the kitchen] *to the other".*

Mattingly (1998), proposes that it is through our body that we gain a sense of order and control. However, my participants' comments support the argument presented by Brosh (2011), that this 'sense of order' may not be possible for people with epilepsy; seizure occurrence often leads to a gap in knowledge such that those affected by epilepsy have to gain a sense of order or understanding of what has happened through the narration of others. Stuart noted, following a seizure that occurred during a night out with friends, how he, "*didn't know anything about it* [seizure] *until the next night when friends came to my Mum and Dad's house to tell them what had happened".* Similarly, Brenda spoke of how her son, *"sometimes tells me when I've had one* [seizure] *and I don't even know".*

For some, this unknown aspect of their epilepsy was associated with a sense of embarrassment:

> *"I'm not a control freak by any means but the control thing is a big part of it - it is definitely that, you know that perception of what people will think of you afterwards, you know"?* (Fran).

This sentiment was also a recognisable thread throughout the accounts given by June. June's attempt to protect 'others' from potential embarrassment as a consequence of her *"blackouts"* was achieved through the use of two key strategies, namely, anticipatory telling (disclosure) and social withdrawal. There is a moral point to June's accounts, which she articulated through various stories of how she told others she was *"epileptic"*; explaining, *"If I take one* [blackout] *with the neighbours I apologise; I'll go and apologise and say I'm awfully sorry about that".* June emphasised that disclosure was not an attempt to evoke sympathy, but rather to prepare others for what might happen. In this sense it was a moral activity which positioned June as protective towards others, *"I've restricted me from them"*. The unpredictability of June's symptoms led her to voluntarily restrict her life more than she perhaps needed to. However, as June perceived the situation, she was protecting others from the consequences of her behaviour: when she *"stares"* she didn't know what she would say or do. It worried her greatly that people might be embarrassed by her actions or consider her rude. Consequently, June believed she was "*an embarrassment to people*" and felt she "*should keep away from people*. June's account resonates with the work of Charmaz (1983) who argued that the need an individual feels to limit social interaction leads to disruptions of their lives and selves that extend far beyond the physical consequence of illness. In accomplishing their daily routines my participants also spoke of other concessions they needed to make, both internal and external to self in order to allow for a sense of control over their lives.

5.2.4.2. Control strategies internal to self

Internal control strategies included exercising self-discipline and the adoption of healthier lifestyle choices, such as better eating habits and reducing alcohol intake. For example, Alan mentioned that, *"I work out upstairs and I don't really eat junk food. I do it for me. I look after me body and everything, so don't drink*." Likewise, Jessica noted that:

> *"If I do have a drink, I have like two glasses of wine or something, or like one drink of wine with lemonade and then coke the rest of the evening. I just think, again that comes down to self-management and self-discipline. I know if I go out and get*

> *drunk, I could end up ill; I could end up with more scrapes. As a result of that my life would just be turned upside down, independence goes, erm…and it's just why risk everything like that when I can manage it* [epilepsy] *myself now"*.

At the time of their interviews, all my participants highlighted the importance of ensuring adequate sleep and rest as a means to managing everyday life. Ricky noted that, *"sometimes it all catches up after a few days and sometimes I can't really sleep properly and I get headaches and with all that I get like mood swings".* Efforts to control his sleep pattern were not always successful and Ricky expressed concern that when tiredness did catch up with him, *"the kids only have to do like the slightest little thing and I just fly off on them".*

Brenda explained that for her, managing day-to-day living with epilepsy meant she *"chose a quiet life".* This was a decision borne out of physical necessity. However, as a mother, it was also a decision she felt guilty about and one she believed her son, when comparing her lifestyle to the lifestyles of his friends' parents, didn't really understand:

> *"All his mates' parents were going out on the town and having a good time and I said* [to son] *well I could do that but I haven't got the energy. I mean I'm in bed before him half the time, at night…and I think is it natural for him [son], for his mum to be doing that? It isn't really, erm…but I think, well I hope he understands it. I mean last night I were ready for bed at half past eight and sometimes I mean I do, I mean, I fall asleep in chair purposely to stay up with him".*

Previous research indicates that compromised sleep and its consequence on daily living is common among people with epilepsy (Mendez et al, 2001; Sander, 2005; Snape et al, 2015). Interactions between sleep and epilepsy have been attributed to a number of potential causes, including insufficient sleep syndrome, poor sleep hygiene, co-existing sleep disorders, the effects of seizures themselves, and the effects of anti-epileptic drugs (Bazil, 2003). The role of sleep disorder for impaired quality of life in people with epilepsy has been previously highlighted by patients directly, as have their concerns over the possibility that anti-epileptic drug treatment may initiate or aggravate sleep problems (Fisher et al, 2000). The identified sleep disorders that are common in people with epilepsy are frequently missed by clinicians (Bazil, 2003). Treatment 'success' in epilepsy therefore must include successful management, from the patient's perspective, of comorbidities including sleep disorders (Sander, 2005).

Within the context of the current study, in coming to terms with the limitations of body and mind in relation to daily activities, many participants reflected on how they used all their energy to cope with their working day and consequently spent the majority of their free

time either resting or sleeping. Over half of my participants - Brenda, Fran, Karen Larry, Martin, Ricky, Stuart and Yolande - had chosen to relinquish being in employment to better manage their daily routines. Yolande reflected on her realisation that her role as a school teacher had become too much for her to manage:

> *"I knew I was on to a bad thing when I (pause)…I wet myself in class, and I thought that's it, I'm going to have to pack in for a while and err…so I did and that's when I went on sick leave and I extended it and just packed in teaching. I felt safer not teaching and that was about twelve, thirteen years ago now".*

For these participants the losses that accompanied quitting employment - for example, financial problems due to a reduction in income and altered perceptions of self[13] from seeing themselves as not being a fully functioning member of society (or, as Brenda put it, being perceived as a "*Skiver*") - were often counterbalanced with gains; they now had increased energy enabling them to participate in family life and social activities that lay beyond the working day.

5.2.4.3. Control strategies external to self

Other strategies adopted by my participants, external to them but directed at managing their epilepsy, included strengthening both familiar and medical resources. The significance of familiar resources was played out in stories that involved family, friends and co-workers; as well as stories about establishing new sources of support through involvement in new (post-diagnostic) activities and social networks. Seeking out other or alternative medical resources signalled a shift in the narratives of some participants. They positioned themselves as 'active seekers of change', each of them combining a variety of medical resource options. These included, for example, seeking out information about the condition from medical literature and the media, gaining information and shared experiences from acquaintances and peers, and actively seeking to establish professional, medical and surgical alternatives to their current healthcare regimes.

Familiar resources

Support from others was both recognised and reported by participants as a means to facilitating a positive change in quality of life and maintaining continuity with the pre-illness self (Charmaz, 1983). Nearly all my participants, with the exception of Yolande and William,

[13] Perception of self and identity will be discussed in greater detail in Chapter Six

spoke of having at least one person on whom they could rely for practical (e.g. help around the home) and / or emotional (e.g. someone to talk to about their problems and worries) support. This was most often an involved family member. Those participants with partners (Fran, Charles, Ashley, Stuart, Martin and Ricky) tended to rely primarily on them for support, whereas participants who did not have partners (Alan, Jessica, Brenda, Larry, Karen, June) were more likely to draw on wider social ties, including parents, siblings, children, friends and co-workers. In securing a social life for himself, Larry remarked:

> *"Friends helped because I used to sometimes be in the pub and if I wasn't going to be so good I used to say hey I'm not going to be so good, can you take me behind that bar please"?*

Brenda spoke fondly of her friend's mum, who supported her in her decision to apply for a position as a healthcare assistant:

> *"I think it were because me friend's mum she, her daughter was epileptic; had been since she were born and I talked to her about it* [applying for the job] *and she helped me a lot and said you know, you're capable, if they accept you, you're capable of doing this job. So I went, for it".*

At the same time as speaking about the love, affection and friendship afforded them through their social support network, my participants also expressed concern about being a "*burden*" or "*feeling guilty*". For example Stuart was mindful of the fact his wife, a college lecturer, had to return to full time employment after Stuart took early retirement on grounds of ill health. More importantly however, she was caring and supportive and provided Stuart with the motivation to go on, "*she's been marvellous, you know, the support, just marvellous*". Stuart identified his wife as, "*a rock*". He continued, "*If I need her she's here, you know she will do anything to make sure she's here.*" Despite the fact Charles was pleased to be back in employment, (and at the time of our discussions was undertaking training to become a staff supervisor at work), he too spoke of the daily effort his wife made, on his behalf, to facilitate his working day:

> *"She* [wife] *takes me to work; gets up and takes me to work every morning. If it wasn't for her I don't know what I would do. I just wish I could drive. It would just take a hell of a lot of pressure off* [wife] *if I could drive".*

Charles felt guilty about the enduring efforts his wife made on his behalf. He worked from 6am to 2pm and, "*if she didn't have to take me to work, she'd get another couple of hours in bed*". Reciprocity and finding ways of giving back within the relationship were important to both Stuart and Charles (Bury, 1982) and Charles described taking on additional roles -

helping around the home and being more hands-on with childcare (*"I pick the kids up from school and give them their teas)*. Guilt and being a burden were also accompanying emotions in Jessica's efforts to take control and strive for continuity with her previous life. She recounted how after losing her driving licence she was no longer able to share the driving with her travel companion on their journeys to and from work:

> *"When I lost me licence, you know, there was nothing I could do. She* [travel companion] *only lived round the corner; we were on the same bloody close. And I felt that I was putting her in a position where she was having to come out of her way but it was only round the corner. Coz I always felt like I was in debt to her, what have you".*

What emerges from these accounts is the 'double-edged sword' that accompanies pursuit of control of one's self and life in ways that had been hoped for. For example, my participants' attempts to re-gain control and normality often threatened their sense of self by simultaneously heightening awareness of their perceived sense of difference. As Charmaz (1983) notes, this sense of inadequacy, anticipated or assumed, can lead to *'self-discreditation and self-blame*' (p187).

New sources of support emerged in the lives of five of my participants as they progressed through the trajectory of their epilepsy. Brenda reflected that when she was eighteen, "*I rebelled against going to church*"; but that she now drew support from returning to the fellowship it offered. For Brenda, returning to her faith was uplifting and reaffirming:

> *"It helps me…I enjoyed it for me and when I look back over these past five years I never thought I would go back to going to Church but I do get a lot out of it. Faith relates to a lot of things. It's not a prayer or anything, just being there really. It certainly helps me to help others as well; other family, me friends".*

Both Yolande and Karen reported volunteering at their respective local epilepsy support groups, and the value of this activity in self-legitimation:

> *"I felt I was doing something worthwhile because it was for something I was aware of and I knew about".* (Yolande).

> *"I opened an epilepsy club, so I run a club there, well over a year ago now. My life just changed and instead of being in offices, I wanted to help people…helping people and listening to them…erm, it's good".* (Karen).

In a similar vein, Charles became more active through his participation in a youth group, training and coaching a football team. This social interaction and the positivity Charles drew

from these activities was reaffirming; he spoke proudly of his football team and the friendships he had developed with his football peers and fellow coaches.

In another example, Alan, after leaving school, enrolled on a music course at a local college which transformed his life. He stated how since starting college, his life had, "*just been going up and up. I know I can accomplish things, my confidence is the highest it can possibly get*". Alan initially viewed college as a challenge but also recognised the support he received from teachers and friends. He took comfort in the knowledge that:

> *"I don't get scared about meeting people now…on the first day I wasn't worried at all I walked into that college and with my head held up high and just getting on with people and getting to know people. Over the three years I have met more people than I ever have in school and got on with more people than I ever have around school".*

For the participants in this sub-group these newly realised support networks offered opportunities to find meaning and purpose in their lives; to gain a sense of control; and to restore (at least in part) their self-esteem. Indeed by responding to their illness through finding purpose and promoting their sociability, participants were able to feel empowered. Many of their stories reflect a 'transcendence of self' (Charmaz, 1987) which helped them to see themselves beyond their own condition and to integrate broader perspectives into their biographies, thus constructing meaning.

Medical resources

My participants reported that when treatment was seen to be ineffective or did not meet their expectations, they often sought alternative medical providers and treatment intervention(s), as a means of re-taking control of the disruption in their lives. Many participants obtained treatment information about the condition from hospital leaflets, the internet and television documentaries and from talking to others who had direct or indirect experience of the condition. For example, following on from her medication stories (articulated earlier), Jessica spoke of how she challenged 'authoritative others' and in so doing was able to take control over what she considered to be a flawed and constraining medical discourse:

> *"I said to him I don't want you treating me anymore. I said I've lost faith in you. I don't think you take on board anything I've said about the problems I've been having. My epilepsy might be fine compared to somebody you'd probably class as more important because they have like twenty seizures a day but you've got no consideration to what's gone on and I want my case transferred".*

This story, while unique to Jessica, reflects a resistance to those in positions of power (see for example, Foucault 1972; Foucault and Gordon 1980; Hyden 1997). By entering into dispute with her consultant, a person traditionally perceived as an expert, Jessica brought her own knowledge and agency to the conversation, challenging not only the individual consultant but also medical hegemony more broadly. Such challenges to medical orthodoxy were not uncommon in the stories of my respondents. For example, Brenda and Karen both spoke of how they "*just didn't seem to be getting anywhere*" with the treatment they were receiving; and as a consequence both had sought alternative physicians to oversee their care:

> *"Yeah, me and me family felt like they [doctors] were just going backwards not forwards. Erm…so he sent, well he [doctor] wasn't very happy because he was dealing with it, but err…he sent off a referral and I went to the [specialist epilepsy] Centre and that's when for the first time I'd had any real input into me epilepsy because up until then I didn't realise there were clinics like the [specialist epilepsy] Centre. I just thought you went to the ordinary hospitals".* (Brenda).

Karen also spoke of her dissatisfaction with her consultant's "*negative attitude"*; an additional justification, in Karen's view, for seeking an alternative health professional:

> *"I'm really pleased now because he [consultant] doesn't get his prescription book out the minute you walk through the door…he just listens, listens you know? And I've been in there, well been in there for over an hour with him. And he's fantastic and he knows a fair amount about err…epilepsy, he's great".*

For several participants however, their response was passive rather than active; echoed in the sentiment that their clinical consultations were one-sided. As Fran explained:

> *"(…)every time you go in with a problem to me they just up the dosage. Like when this started happening, he [consultant] upped my dosage to 1500 [milligrams] and I didn't do it because I thought I don't think that's going to help you know. You kind of manage it…I manage it myself to be honest".*

Ricky too expressed frustration with the approach of his medical team when he had tried to discuss issues other than medication:

> *"As I say when you go there it's just like here's your tablets, see you in like twelve months, repeat everything like it is still the same. As I say there is no-one to say would you like to come in and we can talk about how it's affecting yer? It would be a benefit if they could help yer. It would be more helpful if they stuck you in a group to do something and put you on little courses on information and things. That might be more helpful than just like come and get these tablets or go on this trial. As I say it's all medicine, medicine all the time. It's got nothing to do with communicating or writing things down, finding out like day to day stuff, how it really does affect yer life*

> *and that. You've been going like for twelve or fourteen years and the day to day stuff is more than really the tablets but as I say yer just repeating yourself. Your life changes more than what the tablets do and it might change more if you could find out what other people think. It might take some of the stress off".*

With regard to Ricky's belief about the potential benefits of information and support groups, an early study (Arnston & Drodge, 1987) of the stories told in epilepsy support groups revealed that communication in self-help groups was effective in enabling participants to generate a sense of control over their lives. The implication here is that by creating space for sharing stories, self-help groups facilitate the process of creating meaning for life with epilepsy. Similarly, sharing experiences in open discussion with peers was found to be valuable in research conducted with prostate cancer survivors (Arrington, 2006).

Surgery

Four of my participants – Alan, Ashley, Karen and Brenda - had opted for resective brain surgery. Although each had different symptomology, each participant's health status together with their perceived moral obligation to attain 'normal' health played a role in this treatment choice. For example, Alan explained that, "*Mum and Dad wanted to see whether I could have surgery and I said yeah, I will have surgery, I want to get rid of it*". Alan recognised that having surgery held the potential to change both his health status and the level of anxiety suffered by his parents because of his condition permanently. The successful outcome of Alan's surgery meant that he could now get on with his life and try and "*make something*" of himself.

> *"I know they* [Mum and Dad] *didn't like me having epilepsy it was kind of upsetting them so I wanted to do it for me and for my family…I wanted more* [from life] *as well. I just wanted to get on with my life".*

Ashley too opted for resective brain surgery, both as a means to control her seizures and to lessen the burden she felt she was for her daughter:

> *"I just wanted to get rid of the seizures and I was fed up of her* [daughter] *having to look after me, you know, it wasn't right, the age of her, having to look after me. It wasn't nice putting her through it".*

Karen described herself as active in seeking out surgery. Having searched the internet and read a newspaper article about it, she saw surgical intervention as a potentially life-changing opportunity which gave her hope:

> *"(…)just knowing that there was an operation around which could get rid of it (seizures) was YES! There's a light at the end of the tunnel".*

Even though the outcome had not been entirely successful, Brenda explained that she had not regretted her decision to go ahead with surgery. She had searched for information about it on the internet and discussed it with her medical team and her family. Her family thought her very brave given everything she had already been through with her condition, but as Brenda went on to explain:

> *"(…)I had to do it* [resective brain surgery] *to see if it worked, but also when I'd done it I felt I'd achieved something, actually doing it. If there was anything that was going to make it better then I had to go for it".*

Brenda noted, *"I had to have it done* [resective brain surgery*] because if it had worked it would have been great".* She also acknowledged that her attempts to take control of her treatment choices meant that *"after having it done"* she was able to "*accept the epilepsy more".* This point resonates with the findings of Jacoby (1996) in the MRC Anti-epileptic Drug (AED) Withdrawal Study. Here, few participants who relapsed following AED withdrawal expressed any great regret at attempting to withdraw. Jacoby concluded that:

> *"(…)once the question of their continuing need for AED therapy had been resolved and their treatment regime re-established, they were able to feel more in control of their condition than those who relapsed in spite of being on treatment".* (Jacoby, 1996, p330).

One narrative offered a noteworthy exception to the stories articulated above. While Ricky had been offered resective brain surgery as a treatment option for his epilepsy, he felt unable to accept the risk undertaking this procedure presented to him. He reflected on the alternative strategy he had chosen for himself; *"(…)I've done every [research] trial going".* Ricky's willingness to participate in numerous clinical research drug trials had been his way of trying to facilitate a positive change in his quality of life. Unfortunately, according to Ricky, his efforts had been thwarted, his epilepsy remaining as troublesome as ever; and he no longer knew what to do. Ricky saw bringing about a change to his physical and / or emotional wellbeing as *"being out of my hands"* and under the control of a higher power.

5.3. Chapter summary and implications

For many health professionals the marker of 'success' in the treatment of epilepsy is to be freedom from seizures (Sander 2005). However, for many individuals affected by epilepsy this treatment goal likely falls short of success. For most individuals within this study, their

response to epilepsy was mediated by the context in which it was experienced. Fear and anxiety about potential seizure occurrence, adverse effects related to anti-epileptic drug regimens and social stigma all constituted important issues over and above attainment of seizure control. The common set of experiences of my participants was represented by the four components of the epilepsy plot line, as demonstrated through this chapter, namely: discovery, the search for a cause, negotiating risk and uncertainty, and striving for (even if not always actualising) control.

Participants' accounts can be characterised as sharing experiences, but not answers. These stories have implications for knowledge and understanding around epilepsy care provision, and how illness meaning is created by those affected by epilepsy, their social relationships, and their experience of identity and identity loss. For treatment to be considered truly successful by those with the condition, health professionals must engage with them beyond the level of 'clinical / medical' management and, where possible, address those issues that adversely impact their quality of life.

Within this study, while the individual stories differed, a common thread was the experience of limitations in the structure of explanation around epilepsy. In searching for answers, my participants often found themselves having to come to terms with the limitations of medical knowledge. Examples included: where the cause of their epilepsy was unknown; where medication was ineffective in securing seizure remission or reduction; where drug side effects impacted negatively; or where there was uncertainty about the relative value of different treatment regimes (Charmaz, 1983). Another common thread was information seeking as a strategy to enhance understanding and control of their condition. However, my participants often experienced a contradiction between the application of medically derived logic associated with medicine, for example where non-compliant behaviour exacerbated seizures, versus their own contextual knowledge and lived experience, where compliance did not always prevent seizures. This meant that participants were not always rewarded for doing the right thing.

As a consequence, gaps in professional knowledge and understanding became plugged with lay theories - with participants drawing on their own knowledge and biography to secure a coherent explanation of their experience (Williams, 1984). My participants' desire to identify a tangible link between epilepsy cause and effect confirms the argument offered by Brody (1987) that patients need an illness explanation that sits within the context of their

own beliefs, in order to create a therapeutic coping narrative. This process can be likened to Mildred Blaxter's (1976), 'strain towards rationality'. In her general study of disability she writes how individuals made:

> *"strenuous attempts to see their medical history as a whole, to connect together everything that had happened to them in an attempt to provide a coherent story, in which effect followed cause in a rational way. There seemed a deep need for people to be able to make sense of their world"*. (Blaxter, 1976, p221-222).

The stories that my participants told also lend support to earlier theories confirming the stigma particular illness labels carry. A number of authors (Arnston &Drodge, 1987; Brody, 1987; Sontag, 1990) have previously highlighted chronic conditions such as 'cancer' and 'epilepsy' as having the power to carry negative connotations that, when applied to those affected by the condition, can 'spoil' their identity (Goffman, 1963). Some of my participants expressed discomfort with the word epilepsy, preferring instead to use lay descriptors for their condition and / or symptomology as a means to dilute the negative effect of the epilepsy label. Through varied and disparate situations participants found themselves in, their stories serve to demonstrate the continuing problem of a spoiled identity and the uncertainty and fear associated with the risk of having another seizure. Further consideration of the elements of epilepsy stigma, its meaning and consequences will be discussed in Chapter Seven.

For the majority of participants no dramatic shift in identity occurred at point of diagnosis. That there was not always an immediate pre- post diagnosis identity shift is a departure from other illness narratives (Asbring, 2001). Rather, my participants' stories depicted identity change evolving over time, as the tangible restrictions of having epilepsy became constant reminders of diminished independence and as my participants attempted to resituate themselves in the outside world. Being diagnosed with epilepsy also introduced a sense of uncertainty and marked the beginning of participants' roles as 'seekers of change' in an attempt to re-gain control of their lives, particularly in relation to work and social life. This will be discussed further in the following chapter as the concept of biographical disruption - those structures in everyday life which become disjointed (Bury, 1982) - where the consequence for one's identity or identities is explored. The disruption and illness experience of epilepsy is shown to be context-based: and as such participants found it necessary to adapt their identity accordingly. Thus, identity transformations as a response to chronic, stigmatising illness can be multiple, partial or complete.

In the remaining analytic chapters (six and seven) I aim to illuminate the challenges faced by my participants and to offer insights into the biographical work they undertook in their continued efforts (successful or not) to come to terms with their condition and to bring about improvements in daily functioning.

CHAPTER SIX

6. The lived experience of epilepsy: stories of identity, biographical disruption and reconstruction

6.1. Introduction

As I worked to understand my participant's stories I became aware that questions about the meaning of epilepsy were not always apparent at the point of diagnosis rather, its implications for the lives of my participants emerged as they re-situated themselves within the various contexts (actual and interpreted) in which they attempted to live.

As participants spoke about their experiences, choices and actions it became clear that epilepsy imposed barriers to daily living and to maintaining a positive sense of self. What emerged first and foremost in all these tellings was that they were stories of disruption. This narration of physical, emotional and social events reflected my participants' understanding of how life should be lived, set against cultural discourses about 'normalcy', such as, for example, the discourses on womanhood and manhood, family, age and self – what Somers and Gibson (1994) refer to as 'public narratives'. As such these stories not only portray disruption to a person's life-course but also disruption to their identity. In this way they are not so much stories of illness, as stories about a life disrupted and undermined by illness – what Bury (1982) refers to as biographical disruption. Bury (1982) further argues that such disruptions in people's systems of explaining and giving meaning to events in their lives, requires a *"fundamental re-thinking of the person's biography"* (p169).

The aim of this chapter is to set out how the adults with epilepsy in this study created new concepts of identity after the onset of their condition and how, and to what extent, they were able to come to terms with their acknowledgement of those aspects of identity that had been lost, remained or were added; but required also consideration of the resultant redefinition of a new (sometimes only partial) identity, borne out of new situations (Corbin & Strauss 1987a, 1988). This chapter explores participants' stories of disruptive experience coinciding with the diagnosis of epilepsy. Other stories highlight the continuing disruption and disruption participants' experienced to their future biographies, culminating, in some instances, with their awareness of new insights and other illness gains.

6.2. Stories of biographical disruption

The diagnosis of epilepsy can be considered a disruptive life experience. People with epilepsy come to understand that they have to learn to live with their condition. Relationships with loved ones may be compromised (Ellis et al., 2000), those affected by the condition may find themselves having to cope with the consequences of negative stereotyping (Jacoby et al., 2004), and, the restrictions epilepsy and its treatment imposes will likely impact on daily life activities such as driving (DVLA, 2014) and employment (Baker, 2007).

As I discussed in Chapter Two, biographical disruption can impact on an individuals' sense of self both consequentially (for example, in relation to the practical management of symptoms and / or the illness intrusion on family and social life) and in terms of its significance in relation to the symbolic imagery carried by a particular illness (Bury, 1988). My participants often merged these two concepts of disruption - consequence and significance - when narrating the tensions they had experienced in attempting to live up to expectations about normalcy and the subsequent meaning they attached to living a life with epilepsy. As Brenda said, *"It's not just the actual seizures; it's living with epilepsy".* Implicit here is the multi-dimensional meaning of epilepsy; not only concerning the practical but also the emotional and moral consequences of managing her condition which are embedded in everyday life. This resonates with the work of Bury (1982), who suggests that in light of disruptive experience, the main issue for many people with chronic illness was *"learning to live with it"* (p173).

6.2.1. A counter-narrative to disruption in the experience of epilepsy

Before venturing further with my exploration of the concept of epilepsy as biographical disruption, a counter-narrative to this concept, offered by three participants, deserves consideration. Yolande spoke of the impact of epilepsy as being *"Just part of life's rich tapestry"*. The use of this metaphor serves to demonstrate the importance of context. As a shared story line it was evident that epilepsy did create moments of disruption in the lives of Yolande, Larry and Martin but that this disruption took its place amid other compelling concerns, such as, for example, tensions within intimate social relationships, economic struggles and other co-morbid conditions.

The importance of context is noted in the work of other researchers (Williams, 2000; Faircloth et al., 2004), during their explorations of the concept of biographical disruption. These authors suggest that individuals with pre-existing conditions of ill health may not experience the onset of another illness as biographically disruptive. Rather, they experience it as one event in an ongoing series of life events. Hence Faircloth and colleagues (2004) refer to 'biographical flow'. They argue that the concept of a 'hard life', where general misfortune and material deficiency prevail, or where ill health is anticipated as a consequence of circumstance, may even be biographically anticipated. Such circumstances position the onset of chronic illness as just another component of experiential difficulty; not amounting to a fundamental and profound biographical disruption but rather one of continuity and normality (Pound et al., 1998; Faircloth et al., 2004; Hopkins, 2004; Richardson et al., 2006). It has also been argued that in some instances, those experiencing more severe forms of epilepsy may adjust to the effects on their lifestyle more positively than those with infrequent seizures (Hermann et al., 1996).

Other writers however have cautioned against assuming that those experiencing a 'hard life' do not experience illness as biographical disruption (Sinding & Wiernikowski, 2008). As with the current study, timing of illness onset during one's life course and life stage reflections and evaluations have also been found to mediate an individual's perception of biographical disruption (Grinyer, 2007; Wilson, 2007a). It is important therefore to remain mindful of these challenges and circumstances and not to assume the concept of chronic illness as biographical disruption as being universal. That said, for the majority of participants within this study, their stories suggested that the disruption of epilepsy and its concomitant problems had no parallel. As noted earlier, such disruption was not always immediately apparent in participants' accounts of onset and diagnosis; but the accounts of four participants - discussed in the following section - did suggest immediacy.

6.2.2. Biographical disruption in the accounts of epilepsy onset and diagnosis

The accounts of Charles, William, Alan and Jessica positioned the onset and diagnosis of epilepsy as a critical disruptive experience in their lives. In the early part of his interview Charles talked about the circumstances around his discharge from the navy, and recounted his devastation at *"getting the diagnosis"* and learning that he was *"going to be disabled from the service* [Royal Navy] *all in one day".* Charles continued:

> *"I wasn't allowed to work. I worked on the Sea Harriers, so they stopped me working until a full diagnosis was achieved. Erm…then they took me into a room and gave me the diagnosis…I was upset with the diagnosis 'cause I knew I would have to be disabled through the Royal Navy. So that was it really as far as the diagnosis was concerned".*

His nocturnal epilepsy diagnosis lead to an 'enforced' lifestyle change for Charles - his immediate medical discharge from the Royal Navy. As he explained:

> *"They told me that I wouldn't be able to carry on doing the job I was doing in case I had a seizure during work because they weren't sure whether it was fully sleep diagnosis or whether I could have one [seizure] during the day as well. They said they couldn't actually take a chance because of my job. So I was actually disabled from the service and was only in the Royal Navy for, what, three years"?*

I asked Charles if he had been offered alternative employment opportunities within the navy. He shook his head, responding:

> *"I asked them if I could do a careers office employment but they just said 'no'. It was just straight 'you are going to be disabled from the service' and that was the end of it. I mean it really upset me, I was cut up about it, so when I come out of the service I applied to British Airways, but they said that the qualifications I had in the Royal Navy weren't compatible with the Civil Aviation Authority and things like that, so that was it really".*

Charles continued to express the devastation he felt at that time:

> *"(…) you're just shattered, aren't yeah. I mean I joined [the Royal Navy] because it was something that I wanted to do and just to get the diagnosis, the result that you were going to be disabled from the service all in one, one day. It's just, what can you say, you just don't know what to do".*

Epilepsy and its consequences entailed Charles having to completely re-organise everyday life and to come to terms with his lost identity as a Navel Aircraft Technician. Charles spoke of the changes this disruption brought to his 'taken for granted' future as a member of the armed forces. He articulated this experience in terms of loss; loss of his career and loss of his naval friends. Charles's stories of loss and medical discharge resonate with the regressive narrative form (see Chapter Two, section 2.6.1.) identified by Gergan and Gergan (1986) and Robinson (1990) and serve to emphasise the extent to which the possibility of Charles attaining a personal goal was, at that time, receding.

For William it was after being informed that he would lose his driving licence for twelve months, following his diagnosis that the potential disruption of epilepsy began to sink in.

William explained that he was driving his postal van when he just, *"blacked out".* He continued:

> *"I was there but I just drove straight through a set of railings. Erm…so I came round in the back of an ambulance and I felt confused about what had happened".*

Following a second seizure, William's epilepsy was confirmed. He reflected on the consequences of receiving this diagnosis:

> *"(…)the main thing that bothered me was losing my licence. Particularly with it being me job. I couldn't do me normal job in work".*

William explained that he tried to remain positive following his diagnosis, noting:

> *"I've had two [seizures] in the six months, fair enough, but I have also learnt that 50% of people who have a fit never have another one. So that's sort of, that reassured me".*

In coming to terms with the situation that had arisen, the biographical work undertaken by William involved an acceptance of his condition so that it became an integrated aspect of his identity. He disclosed his epilepsy to his bosses and work colleagues, who he reported as being very supportive of his altered situation. As such, William was able to negotiate alternative working practices, taking on a walking postal round in place of his previous driving postal round. This opportunity to swap roles with a colleague enabled William to maintain his independence and his employment status. Unlike Charles, biographical disruption for William was not so pronounced as he was able to retain his job and the links he valued with his team of co-workers and maintain (at least in part) aspects of his previous social identity, that of 'worker'.

Immediate disruption for Alan and Jessica was played out emotionally rather than experientially. Both recounted anticipatory fears of what a diagnosis of epilepsy might bring with it in relation to their future. Alan expressed concern about how it might affect his life generally:

> *"I just didn't want to have epilepsy for the rest of my life, where it could have stopped me doing some things…like driving and everything",*

And, more specifically, in relation to friendships:

> *"I didn't want other people to see me as a freak of some kind, because I'd got epilepsy. I didn't want them to like think I was a weirdo and turn on me and think*

> *'Oh he's a freak because he's got epilepsy'. I'm a strong person inside and it was just I was more worried about what people would think of me".*

Although Alan perceived himself as sufficiently physically resourceful to cope with his seizures, his disruption to sense of self was manifest in thoughts and fears of how others might perceive him. He feared such reactions might call into question his social credibility. As Alan's seizures became more visible to his peers his strategy for re-constructing his sense of self was active disclosure: *"I just decided to say, 'I've got epilepsy'"*. Such *'instrumental telling',* according to Schneider and Conrad (1980, p39) is an individual's attempt to mitigate the potentially negative impact of epilepsy on one's self and in daily life. For Alan, the driving force behind this strategy was to manage the situation of having seizures by increasing knowledge and understanding of his condition among his peers. Alan went on to explain:

> *"If I had an attack in front of them [fellow students], I wanted them to know what was happening and not to worry about me. I wanted them to know I can handle it* [seizure] *myself. And so they just don't think I'm a weirdo…I just don't want them to think I'm a weirdo and just let them know that I am having an epileptic fit".*

This fear of other people's reactions or felt stigma (Scambler, 1989; Jacoby, 1994) not only constituted a threat to Alan's identity but appeared to be experienced as a greater burden than his epilepsy itself. This resonates with the work of Kleinman (1988) who noted that stigma begins with the acceptance of a stigmatised identity. In the short term Alan's strategy of telling, as a means of being accepted, worked for him; he reported his fellow students as being *"understanding"* and *"very supportive"*. However, along his journey of adjusting to and accepting his condition, Alan described experiences of both enacted and felt stigma and its consequences. We will see throughout this chapter how the concepts of identity and stigma appear intrinsically linked. I shall however, explore the concepts of epilepsy stigma in greater depth in Chapter Seven.

Jessica's fears of what a diagnosis of epilepsy might bring with it appeared more widely dispersed, with varied concerns about how to manage the uncertainty of her altered situation in everyday life. Reflecting on the contrast she felt between her current and her pre-epilepsy life she said, *"It was frustration that I had it and it made me different in the sense that I had this label but didn't know anything about it".* Jessica felt that the activities and independence she had previously experienced as part of her life style now alluded her:

"(…)and then of course parents go into protective role and you know, it's 'you shouldn't be doing this, you shouldn't be going out into town', and all this kind of palaver, and 'don't be having baths on you own'. And in a way erm…I know parents look out for you, because you're their kids at the end of the day and stuff like that, but I was really knaffed off because it was like my independence. Because the fact that I couldn't do the driving, the fact that Mum and Dad were sort of like erm…'you shouldn't be going out into town on your own, you shouldn't be going swimming on your own' and all this type of thing. And I said to the Consultant I'm pissed off. I said because it's like being wrapping up in cotton wool, and I just can't do it, because I feel like it's, you know, its epilepsy as opposed to Jessica. And you know, Mum and Dad would probably be heartbroken if they could hear me talking like this, but it was that thing that it was over protective".

Disruption and loss were spoken of to the extent that Alan noted his previously happy life and *"normal childhood"* was *"all shut down"* and Jessica said*, "(…)when I had my diagnosis I always described it as having your wings clipped".* Metaphors are one way in which individuals can use language as a means of making sense of experience and of expressing meaning (Punch, 1998). In this instance the metaphors used - *"all shut down"* and "*having your wings clipped*" - not only expressed the difficulties Alan and Jessica both experienced in maintaining their earlier levels of activity but also communicated their perceived loss of independence and their concern with regard to the potential for increased reliance on others. As a shared story line across participants' narratives of continuing disruption (see section 6.2.3.), these metaphors were represented in accounts of dependency on others and loss of independence in relation to self.

For both Alan and Jessica it appeared that their sense of disruption became all the more poignant as they came to comprehend the potential restrictions epilepsy placed upon them and compared themselves against social and cultural discourses about 'normalcy' (Somers & Gibson, 1994). Both associated their experience of disruption as borne out of 'cultural stereotypes' held by others. For example, as teenagers, they positioned themselves as people who were keen to socialise, to stay out late at night, to drink alcohol, and to learn to drive; and so were perceived thus by their peers. The ensuing conflict both of them felt between the expectations of others and their own knowledge and experience of living with epilepsy - namely, of needing to ensure adequate rest and sleep, needing to be careful with alcohol intake, and of having been deprived of a driving licence, served to heighten a profound sense of difference. As Scambler (1992) noted, an individual's epilepsy clearly has more salience for them in certain roles and in certain situations than in others. The changes in circumstances, for both Alan and Jessica at this point in their lives, gave epilepsy enhanced salience.

As an example, Jessica recalled the frustration she felt at having to surrender her driving licence to the DVLA:

> *"I remember going to the doctor and being completely pissed off because I'd started my driving lessons and I'd had two and was due to have another the next day and she* [doctor] *said 'absolutely, no way, we need to find out what is going on' and I just remember being totally, totally pissed off. I was completely pissed off about my driving licence, err, because all my friends were all getting their driving licences and doing the lessons and sort of passing their test and I thought, well why me? If I try and prioritise it, it was like my driving licence that I was annoyed about, the loss of me independence, the loss of driving and relying on everyone else; that was a big thing for me".*

Implicit in this story is Jessica's awareness of her diminished independence and the loss of the things she valued. Driving would have offered proof that her life was not entirely restricted by developing epilepsy but she no longer felt able to exercise freedom of choice in this valued activity; a sentiment expressed by a number of my participants. As Charmaz (1983) asserts knowing that one *"can no longer drive or function in other ways that symbolised independence prompts the realisation that life is becoming increasingly restricted" (p172).* Her observation of her mother's *"frustration at having to use the bus"* while her car was *"temporarily"* in the garage for repair, revealed Jessica's view of the restrictions imposed upon her by not being able to drive. As she said, *"I told her* [mother], *now you know how I feel"*.

Alan and Jessica's stories provide good examples of how onset and diagnosis may not only create disruption to current biography, but carry the potential to create disruption to future stories of self (Travers & Lawlers, 2008). As such, these stories mark what Bury (1982) refers to as a *"biographical shift from a perceived normal trajectory through relatively predictable chronological steps"* (p171) to one that differs from the expected.

In the following section I will explore the broader significance of the suffering experienced by participants over time, both in relation to biography and identity.

6.2.3. Stories of continuing disruption(s) to biography and identity

In attempting to illuminate how my participants' bodies and selves were affected by disruption and the biographical work done, I have chosen, in this section, to represent participant accounts as a collective. The plot(s) are not positioned temporally - as with the dominant plot identified in Chapter Five; rather the analysis is presented within topic-centred plots and storylines, as a means to illustrate how medical, physical and

psychosocial conditions and contexts contribute to disruption. Within these shared plots I consider the differing positions of narrators as a means to highlight the heterogeneity of their experience, while at the same time demonstrating how their epilepsy narratives have the power to transform individual experiences into collective experience. In this sense:

> *"illness experience is removed from the private sphere and becomes part of an all-encompassing, political and social narrative in context".* (Hyden, 1997:p59)

In some instances, a particular informant's story is shared in greater depth. The purpose of this mode of presentation is to illuminate understanding in relation to how experiences are reflected over time (Riessman, 1993), and as a means to understanding disruption as it develops out of daily life and in relation to its effects on the consciousness of individuals concerned. Thus, the narrative is able ask what the social implications of epilepsy are. I also consider the plots and storylines in relation to existing epilepsy and illness narrative literature.

6.2.3.1. Epilepsy: an unanticipated event

Sanders and colleagues (2002) articulated chronic illness in older adults with joint disability and pain as sometimes being an anticipated event. Arthritis was generally perceived as being synonymous with old age, with the investigators reporting that respondents seemed to play down its significance, seeing it as being 'normal' given their age. A similar position was reflected by respondents in the study by Pound and colleagues, (1998) of elderly stroke sufferers who reported that *'things aren't that bad'* (p495). The contrast to this position of an 'anticipated event' for participants in the current study was evident in the experiences they described, irrespective of age at onset of epilepsy.

Epilepsy was an unanticipated event, with participants' stories following onset highlighting continued disruption or losses, suggesting disruption not just for them personally but also to the 'normal' trajectory of the family life cycle (Carter & McGoldrick, 1999) which was often challenging for both them and significant others. Alan, for example noted:

> "*It feels like when I got diagnosed with epilepsy, it felt like the family got diagnosed with it as well. Because, they had to live with it. They had to live with me having the fits and everything. I'm not saying like they got fed up with me having the fits or anything but like when it first started and everything I was like waking up me Mum and Dad, running to me Mum and Dad when it was happening? Running to me brother and like sometimes it does feel, it does feel like they've got epilepsy, like they have it as well".*

Ashley expressed concern about the wellbeing of her young daughter, who could potentially be *"left home alone"* during Ashley's seizure events:

> *"I was having loads* [seizures]*, quite a few a day a lot of the time. When I got this [house] it was 5, 5 or 6 years ago and she* [daughter] *was only young then. It wasn't fair on her; well she couldn't have been left. If [husband] was at work, and she* [daughter] *was in here with me and I had a bad one* [seizure]*, then she would just ring up and say me Mum's not well and me Mum would come down".*

Ashley noted that as her daughter grew older, she became more aware of her mother's epilepsy; a situation which created anxiety for them both:

> *"She [daughter] was having to come to town and everywhere with me. It wasn't nice for her. She was worrying and saying 'Are you all right Mum. Are you all right?' You know, but all the time".*

Similarly, both Brenda and Ricky noted the burden of increased responsibility that having epilepsy placed upon their children:

> *"You are more, more wary of what yer doin and that. With having 2 kids, they like pick up on it coz they have got to like watch me. They ask questions like, 'how come yer lips are blue' and all that and they've been told like if me lips go blue and I start acting strange just to like sit me down and all. So they have got to be like adults…the kids had to be more grown up because as I say, they had to watch me".* (Ricky).

These stories speak of change in the roles and responsibilities of the younger children of participants in this study. In the above quote, Ricky acknowledged the reasons for this on a practical level while in a linked 'swimming story' (articulated later in this chapter) he struggles to relate to this situation himself:

> *"(…)but it doesn't make yer feel like too good does it when yer got kids looking after you. As I say with being the adult you should be the one looking after them…".*

Often these stories were suggestive of difficulty with the concept of what may be termed 'role reversal' – depending on others, who in their eyes, should be depending on them. It seems it is the very dependence on others that is seen as a major challenge to sense of self.

In Chapter Five I described participants' attempts to negotiate the risk and uncertainty that epilepsy created in their lives, and their efforts to re-establish control of the unexpected as a means to maintaining continuity. These stories told of participant experiences around gaps and conflicts in information provision and treatment advice offered by health professionals, of participants' ensuing struggles in raising matters which were of concern to them, and of concern expressed by many participants around the propensity for seizure

occurrence. This meant that living with epilepsy on a daily basis carried consequences with potentially negative impacts on participants' functional and emotional wellbeing. I will not re-iterate these stories here other than to highlight that such experiences also contributed to the disruption my participants lived through. When recounting their experiences, participants explained how epilepsy, either directly or indirectly, affected a number of aspects of their lives, and shaped their identities in relation to family, social and working roles. Thus the disruption of epilepsy and my participants' attempts to regain control varied in significance and brought with it various consequences for different participants.

Throughout my participants' stories, biographical disruption was positioned as something that was experienced not just at onset but across the entire trajectory of their epilepsy (Becker, 1997). Alan's comment below provides a further example of disruption as being not just to the individuals' sense of self, but as resonating through the lifestyle systems (in this example, family, school and friendship systems) participants were engaged in (Chamberlayne & King, 1997; Richardson et al., 2006):

> *"I hate it when my Mum makes a fuss. It annoyed me when people outside made a big fuss of me. When I was having the fits in school and friends were like making a big fuss and now it's my girlfriend…I told her that if I have one* [seizure]*, when she first slept here I said if I have one, turn over, go back to sleep. I hate being made a fuss of because it felt like I wasn't able to like handle it myself. When I knew for a fact I was".* (Alan).

Bury's (1991) concept of coping is relevant here for it considers how individuals manage the unexpected trajectory of illness and try to maintain *" a sense of value and meaning in life, in spite of symptoms and their effects"* (p461). Bury (2001) suggests that two courses of action can be undertaken to promote normalisation and dilute the impact of one's illness on identity. In the first, people 'normalise' through maintaining as many pre-illness activities as possible; and keep their identity intact by disguising their symptoms (a strategy which may prove difficult for people with epilepsy due to the potential visibility of seizures). Others identify ways in which they can integrate their illness so that normal life is re-constructed to contain the illness.

6.2.3.2. Epilepsy: the need to battle through

The desire to promote normalisation was evident in the process of narrative reconstruction of their disrupted lives described by the majority of my participants. *"Battling through"* and "*fighting"* were common metaphors used to indicate the degree to which they strove for

normality. For example, Martin commented that, *"I just battled through it".* Stuart noted how *"It was a lot to cope with*. *I just battled through when I was younger"* and Jessica and Brenda both spoke of *"fighting the epilepsy"*; metaphors which reflected the personal efforts required by each of them in maintaining employment – *"dragging"* themselves into work with the determination not to accept any disruption.

Jessica also spoke of the disruption she felt in relation to her career as a probation officer as being *"a constant uphill battle"*, particularly in relation to managing her sickness absences from work, her frustration and the inconvenience associated with not being able to drive to meetings and what she saw as the unnecessary working restrictions placed upon her by her boss. However, the way she constructed her narrative of epilepsy, *"I think I just sort of floated through life a lot of the time because I didn't necessarily acknowledge what was going on"* and *"it's never stopped me doing anything I've wanted to do"* appeared to minimise the impact of the disruption and could be seen as a way to distance herself from seeming to be someone who was struggling, and to legitimise her place within the workplace. Epilepsy may have been just as disruptive on a practical level but this was not always heard, indicating the role of agenda, self-presentation and performance in narratives as individuals attempt to present themselves as culturally competent (Bury, 1982; 2001). Jessica, while not accepting the consequences of her illness, did not deny epilepsy itself; rather she strove to maintain her social identity, providing her with the means to lessen the biographical disruption she experienced at that time (Asbring, 2001).

Charmaz (1991) showed that work is given high priority by those who were chronically ill. In relation to epilepsy, previous research highlights social losses around underemployment and unemployment and supports the notion that identity is strongly connected with work (Smeets, et al 2007; Holland et al., 2009). Paid work was regarded as an important part of life for several participants in this study. Like Jessica, Brenda too expressed concern about her sickness episodes from work and how her epilepsy might be perceived as representing a profound threat to her competence to perform as a fully-fledged member of a working team. Brenda's ideologies on values of hard work and individual responsibility in relation to maintaining a 'normal life' are discussed in the following section.

6.2.3.3. Epilepsy: a challenge to personal adequacy

In this section I offer detailed accounts of the impact of epilepsy as it encroaches on a person's sense of adequacy. These stories illustrate the different contexts for continuity

and discontinuity and serve to demonstrate how concerns about self are internally perceived and how self is portrayed to others as 'adequate'.

Adequacy as a competent worker: Brenda

While Brenda's experiences are unique, examination of her presentation of a series of linked narratives in relation to employment serve to demonstrate the biographical work undertaken by several participants in retaining those aspects of identity that were connected to having a 'working life'

Brenda positioned herself as a caring person and a loyal, conscientious employee; someone who had always been in paid work. As alluded to in Chapters four and five, Brenda's limited response to anti-epileptic drug treatment and her lack of seizure remittance following surgical intervention for her epilepsy meant that her seizures continued to be unpredictable, frequent and often severe. However, despite the serious physical and emotional consequences of her epilepsy she was someone who did not readily take time off sick.

Brenda had left pre-nursing college reluctantly when she had been diagnosed with epilepsy. Securing a job in a children's home as a carer provided the first positive turning point in Brenda's post-diagnosis narrative:

> *"It was sleeping in, you worked in a team; you didn't work on your own you worked in a team. Erm, anyway I got the job. And I told them all about me epilepsy and that and it was fairly controlled then. But err, I got this job and I loved it. It was brilliant. We didn't get paid for sleeping in. We worked 60 hours a week, but I mean I loved it…we went on holiday with them".*

However, Brenda's attempt to return to activities at the level associated with her pre-epilepsy identity failed and disappointment ensued. In the following story, Brenda deals with her beliefs about the events which influenced the onset of a nocturnal seizure. Her presentation of events, shaped by purpose and context, is consistent with the *'contingent narratives'* identified by Bury (2001) (see Chapter Two, section 2.6.1.2). Such narratives tend to be descriptive in nature, dealing with events as they unfold. In this example, being moved to a smaller unit which necessitated Brenda sleeping in the home on her own provides the context for those aspects of her story around beliefs and knowledge of the factors that influenced the onset of a seizure, and its immediate or *'proximate'* effects on the body, self and others (p268).

> *"I never slept in on me own. It was always a team of us because we had 12 children to look after. Err and they were split up into groups so err, err, but then I had, I got moved to a smaller unit with 9 children in and err it was one, one night…I mean, I'd had a couple [seizures], but not were it would finish me job, if you know what I mean, and like I say they did know about it [having epilepsy]. Erm…but this particular time you slept in and you slept in on your own. I had, had a seizure that one night when I was on duty. Erm, I wrecked me room. I must have been walking, sleep walking, it was wrecked erm…and so… the boss was brilliant. But, instead of him having to finish me I decided to say, coz I knew I wouldn't be able to work in that home again, so I said well I'll, I'll finish. And err… so that was that and I were there for about 5 years".*

While theoretically (Mishler, 1986b; see Figure 3), Brenda offered an evaluative commentary on events in her story - "*instead of him having to finish me I decided to say, coz I knew that it would have to, I wouldn't be able to work in that home again, so I said well I'll, I'll finish* - left questions unanswered in relation to the event. For instance, why did Brenda resign her position and what led to her understanding that she would not be able to work in the children's home again? I responded to Brenda's story by creating an opportunity for further elaboration and asked her to: *"Tell me then, how did you feel"?* Brenda continued:

> *"I was up, I was upset because I loved me job and I really got something out of it. And I was just doing a CSS course at college as well, like a social work course to go that bit further but well…another thing you have to accept in life. But I didn't, I didn't accept it I don't think, all the time. I mean I used to like having a drink, you know, …err I led, I wouldn't say an absolutely active social life but coz I was working and I carried out me job but I certainly didn't stay indoors when I were off duty…so I don't think that helped but that's what you do when you're young. Err, but I held down me job, but then I had to finish, me self I decided to finish, because err, I felt it was unfair really and they'd been good to me anyway. Coz I did feel guilty and I still do, when it* [seizure] *happens now I feel guilty…I just feel like I'm not, not able to do the things that I should be able, that I expect to do…able to do what everybody else does".*

Considering Brenda's initial story and her subsequent elaboration of it as a 'new whole', the narrative re-construction process she pursued highlights, I would suggest, the 'moral' components of experience. A '*moral narrative'*, as defined by Bury (2001), involves *'the inclusion of valuations as sufferers seek to account for and perhaps justify themselves in the altered relations of body, self and society brought about by illness'* (p274). Brenda's work-related narrative is consistent with this position, in that she uses her evaluations (Mishler 1986b) to explain and justify her actions in a way that enables her to present herself as a *'morally competent actor'* (Pinder, 1995, p624).

Through this extended account it can be discerned that despite the intense nature of the work, Brenda enjoyed her job and derived great satisfaction from it. Brenda's strategy of further study (undertaking a CSS social work course) was aimed at sustaining her position in the workplace and functioned as 'proof' of the importance she placed on progressing in her career. Despite the imposition of long working hours and the changed nature of her role, requiring her to sleep in on-site alone (both factors which might reasonably be considered as potential seizure triggers) - Brenda showed herself reluctant to apportion any blame to her employer for the situation she now found herself in. Rather, the narrative form she adopted is suggestive of her acceptance of personal culpability.

The meaning that Brenda brought to her epilepsy thus appeared to extend far beyond the immediate impact of the seizure event (loss of bodily control) to incorporate notions of guilt: firstly, in her expression of concern that her participation in a 'social life' outside working hours may have contributed negatively to managing her symptoms in the context of her working life; and secondly, in her description of how the constraints of those symptoms affected her perception of herself as 'different'. She felt discredited (Goffman, 1968) to the extent that: *"I just feel like I'm not, not able to do the things that I should be able…that I expect to do…able to do what everyone else does"*. The moral weight Brenda attached to her role as worker was depicted through her readiness to accept personal responsibility for her failure to act competently in that role. Her resignation from the job made sense in terms of allowing Brenda to alleviate the impact of her epilepsy on her role as worker and maintain a 'morally' competent version of herself, *"I felt it was unfair really and they'd been good to me anyway"*.

The idea of personal responsibility for continuity in one's life was present in many of my participants' descriptions of the effects of disruption. Take, for example, the disruption to sense of self borne out of what I shall refer to as 'privacy invasion'. Although this term was not made explicit by participants, it was the sentiment expressed in many stories told, for example, of crowd formation following the occurrence of a seizure, of being asked outright about epilepsy or a consequential situation, and in stories of offers of help, deemed to be unnecessary and / or embarrassing - as in the case of Alan, who noted, "*(…)I hate being made a fuss of",* and in stories of being stared at, like that articulated by Ricky:

> *"Most people won't tell you what's happened they just sort of look at ya, as if you're a weirdo or something. I normally see like all the same people* [in the pub] *and sometimes you can see them and they look at ya and you feel…and I think, 'did I*

have one of my things?' But as I say, if I do it when I'm out like, I think, there is something wrong with me, but I don't know what I've done".

These findings resonate with the observations of Becker (1999) who noted that:

"(…)people felt responsible for disruptions that were essentially beyond their control and for righting these disruptions, both at the social level and at the personal level".

Returning to Brenda, after only a short period of unemployment, she secured a post as an auxiliary nurse (again disclosing her epilepsy), at the local hospital where she still worked at the time of the interview, caring for patients with dementia:

"It was amazing really, I put an application form in…So I went, I couldn't believe it, I went for this interview and err,…again, I told about me epilepsy… I brought it all up, I brought it all up about that [having epilepsy] and they didn't, well you know 'So what!' But I got the job and they said right, you start next week…So…I couldn't believe it!"

Having epilepsy was often seen as carrying risk of being discounted. Charmaz (1983) notes that, *"being discounted is closely tied to inability to function in conventional ways*". As a consequence, being discounted is a constant threat where individuals may feel "*compelled to negotiate their identities" (p185*). Here, at the risk of undermining her ability to perform (Charmaz, 1991), Brenda once again voluntarily chose to disclose her condition to her prospective employer; incorporating epilepsy into her identity signified personal progression, as the *"need to deal with changes in identity and self-presentation are part and parcel of the unfolding events"* (Bury, 2001, p278).

In light of previous negative comments from Brenda's college tutor about her inability to pursue a career in nursing as a person with epilepsy, Brenda was anxious to highlight her *"love of work"* and talked at length about her employment history. In what could almost be seen as a narrative of pride, she presented the crux of these stories – namely, attaining and sustaining her place within the workforce - drawing on her personal image of 'nurse' she presented a story of success:

"I can remember to this day the first day I went on duty with me cap on, we wore caps and belts then, err and I'm still, well at the moment I'm off work, but I'm still working for the same place err, but as an activity assistant now rather than an auxiliary nurse. And I loved, I loved it".

The value Brenda placed on working was evident in her comments, which I interpreted as a signal of its significance to her sense of self; work represented an integral part of her current identify and 'normal life'. It was however, an aspect that having epilepsy most

often interfered with. As articulated earlier, one process of 'normalisation' discussed by Bury (2001) involves the incorporation of illness into the individual's changed lifestyle – wherein the stories people tell about themselves are likely to disclose illness rather than hide it. Following Bury's argument, Brenda's disclosure of her condition (in this instance to her employers) signalled a change in identity rather than an attempt at preserving her previous persona.

At forty, Brenda was currently negotiating a retirement package on the grounds of ill health – and retirement at this early age was a difficult concept for Brenda to come to terms with. Her sense of difference in relation to what she considered to be societal norms was heightened by seeing herself as being of working age, but not at work. Brenda's situation was in conflict with normalising ideologies about old age and dependency, and her recognition of societal discourses about age-appropriate behaviour (Becker, 1999). Brenda's sense of difference was also played out on a personal level, not least because the constraints of epilepsy had triggered awareness of further change in her body's ability to perform at its fullest and she was still in the process of reconciling the disruption that the physical consequences of her condition caused. In addition, Brenda's sense of difference was felt through the ensuing guilt she experienced about her inability to work:

> *"I've had to be off sick from work and I'd been off 12 month when I had, when I was told that I couldn't go back doing the job I was doing and the job I love. I had to have someone's professional opinion besides me own that I couldn't do it. There was a lot of stress and a lot of…they [seizures] became more frequent. So doing the job that I was doing was very mentally draining. It's a very, a really deserving job but I know that I can't do it any more for the safety of patients and the safety of me. But I needed someone to tell me that, which was err, the doctor from [name of hospital] and also me GP and friends and family. Erm…because on me days off I was just sleeping ready for the next day's work. I do coz I get tired. There's people around me now, I mean I have a lot of people helping me out. They don't think any worse of me, but it's me thinking, still after all these years still not really accepting it and that's been me problem really. I'm an independent person, always have been and I think that's the annoying part to it".*

Brenda had worked as a caregiver within the same NHS Organisation for sixteen years at the time I first met her. Throughout her narrative, she returned frequently to reflect on the impact of her epilepsy in relation to her working role: she explained the difficulties, *"I really enjoyed doing nights but it just mixed me medication up and err…I think that's what the problem was",* as well as the strategies she employed to manage the significance of her physical differentness on her working life. This involved, for example, re-negotiating shift patterns and re-negotiating her working role from auxiliary nurse to activity assistant. The

value she placed on her employer's responsiveness to her condition and on the friendship of colleagues was evident and served to mediate the negative impact of the disruption(s) she experienced. For example:

> *"I mean I used to do nights and then they said right you don't need to do nights, coz I did have a couple* [seizures] *when I was on nights. It was me pattern, it wasn't suiting me pattern so you can just do days, which I did shifts so…they were good to me that way. We had a good working, err everyone got on with each other well and we used to have nights out err…but I never abused it. I never didn't turn up for work because of odd nights out now and again. I mean the Sister, err well they were all…it was a good working…they were good with me, but I was good, I was good at me job I know I were and err…I didn't you know, I didn't go off sick for no apparent reason, and err…when I did go off sick, a lot of the times it was because of the epilepsy and they didn't pull me up on it really. I can't complain there. They were…it did help me a lot".*

Brenda's work role allowed the realisation of her desire to help people, and had challenged her inner dialogue of self-doubt – *also* assuaged when her capability as a nurse was externally validated by colleagues, *"I said that to a few people and they've said 'Why, why not"?* This external validation process enabled her to reflect positively on changing social attitudes towards employing people with epilepsy. It also represented the proof Brenda needed to internally challenge her former college tutor's view that she was *"not capable of doing nursing"*. As Brenda said*, "I mean the training, if I'd have wanted to do it I would have gone ahead…I didn't want to do it"*.

Brenda's re-evaluation of her previous career goal - to train as a nurse - reflects the relational aspects of her life. The positive aspects of both her working life and her social life allowed her to re-evaluate that original goal and conclude that undertaking nurse training would have changed those aspects of her identity (her job and her life) that she found most fulfilling:

> *"I just enjoy doing what I was doing, being on the wards with the patients. You do your nurse training, there's so much other stuff you've to do other than looking after patients…if I'd have wanted to do it I would have gone ahead. But it would have meant going back to do, to do… leaving it all and I just couldn't to do that. I was enjoying life, you know enjoying me job, but also enjoying life… and I look back and think 'do I regret it?' I don't, I don't regret it because we had a, I had a good life".*

Consistent with the findings of Asbring (2001), Brenda's work-related stories highlight that biographical disruptions are not always viewed as entirely negative. Subsumed within an overarching narrative of a disrupted biography stories of morality, pride and success

emerge. Thus Brenda, despite the physical and emotional disruptions she encountered as a consequence of her epilepsy was able to negotiate and come to terms (at least in part) with her new identity. For Brenda, as for other participants, the losses that accompanied leaving employment, for example, being perceived as a *"skiver"* or as less than a fully functioning member of society, were often offset by gains - for example procuring increased energy to participate more fully in family and social activities that lay outside the working day. Ironically, Brenda's experiences brought with them new insights with regard to her own previous life and life in general, in as much as the disruptions she experienced were also reflected upon as positive experience. New insights and other illness gains, experienced by Brenda and others, will be discussed in a later section of this chapter.

Adequacy as adult and father: Ricky

A further storyline, offered by Ricky, also focused on how epilepsy reflects upon an individual as a social being (Corbin & Strauss, 1987a). Its relevance lies in its demonstration of the symbolic implications individuals attach to their condition. Ricky's swimming story makes this point emphatically clear:

> *"It's like bad enough when I go to the baths I have to go up to like the fella in the baths and say that I suffer an epilepsy. So like while you're swimming they can keep an eye on yer in case anything happens. You know what I mean? So like a kid they have got to keep an eye on you, cos you don't know when you're going to have one [seizure]. Cos I could just be swimming and just like stop swimming…but as I say with taking kids yer normally down the shallow end anyway…but it doesn't make yer feel like too good does it when yer got kids looking after you? As I say with being the adult you should be the one looking after them…if something happens to them and I have one of mine [seizure] I can't look after them can I"?*

Ricky's seizures may not have been present all the time but his knowledge of their possible expression and their propensity for recurrence carried huge significance for him not always overtly apparent to others - they became the source of a negative sense of self - one that challenged his public identity both as an adult and as a father. Ricky's experience and the experiences of Alan, Jessica, and Brenda, articulated earlier, resonate with Scambler's (1992) argument that people's epilepsy commonly has more salience for them in some roles and in some circumstances than in others.

Implicit in Ricky's comment quoted above was his evaluative judgement (Mishler, 1986b) of who and what he should be in relation to what he considered to be 'normal' and 'able' – *"with being the adult you should be the one looking after them".* In this regard, his

comment serves also to demonstrate that stories of disruption are by definition, stories of difference (Becker, 1999). Other participants' narratives repeatedly attested to how they viewed themselves in opposition to what they and others saw as 'normal' in relation to their circumstance, age and gender. The role of motherhood was a storyline articulated by Ashley, Fran and Brenda and provides a case in point, as outlined below.

Adequacy in the role of mother: Fran, Brenda and Ashley

All three mothers of young children in this study - Fran, Brenda and Ashley- spoke of the inadequacy they felt in relation to their mothering role. They appeared to carry the burden of feeling unable to live up to the care responsibilities demanded of them by the role, and consequently they felt guilty that on occasion they were unable to deliver the care they believed their children deserved. Fran reflected on her concerns in relation to seizure risk when caring for her boys:

> *"(…)when they were little you know, I used to think, Oh my God what if I was holding them?...this one night I had him in my arms and I remember I staggered over to the cot to put him in the cot because I was terrified I was going to have a fit you know, and I just thought to myself it's there [epilepsy]…every stage of your life it's there, you know? I was so frightened?*

Similarly, the disruptions Brenda encountered as a consequence of her symptoms led her to reflect on her sense of inadequacy as a mother. For as she said, there had been times she, "*felt like an unfit mother".* Disruption in the relationship with Peter, her son, was described in relation to a number of occurrences - the time she fell down stairs with Peter in her arms, her absences from the home as a consequence of lengthy, post-seizure, hospital stays, and the numerous occasions she had felt so unwell, or was too tired to cope with the disruption of having Peter's friends around to visit him at the house. Brenda's perception of her identity and role as a mother appeared to be further compromised when she expressed her belief that she needed her son more than he needed her. Brenda spoke of how:

> *"Sometimes I think if it weren't for him (son) I wouldn't be here. And it's an awful thing to say but…because it's like I feel like I'm using him in a way, to get through. It's him that's helped me through…it is him that has helped me through it, but I love him to bits".*

In a similar vein, Ashley spoke of feeling guilty about the *"carer"* role her young daughter had undertaken. As Ashley said, *"she* [daughter] was *having to look after me".* The burden Ashley felt she placed upon her young daughter, as a consequence of the symptoms of her

epilepsy, "(…)*it just wasn't right".* Bury's (1982) observation that chronic illness not only disrupts structures and their meaning but also disrupts relationships is relevant here. Illness can lead to dependency on others, which has the potential to violate societal norms of reciprocity and mutual dependency.

Recreating normality: Charles

In coming into conflict with the social order of things as they understand it, individuals are required to review and reconstruct their sense of self and social place as a means to regain continuity and control. Striving for control was a component of the epilepsy plot line (see Chapter Five) identified across several of the stories told by participants in this study. As Brenda's work-related stories above demonstrate, the tension between a desire for normalcy and the acknowledgement of being different requires constant repair work that draws on material, relational and cognitive resources.

Charles, in the second part of his interview, moved from stories of devastation at being medically discharged from the Royal Navy, to focusing on his current situation. He spoke of several experiences that contributed to him taking back control and being able to re-create a sense of normality. Overall, the second half of Charles' narrative re-construction conveys progression (Bury, 2001), not articulated in terms of specific 'key turning points' as such, but rather in terms of his day-to-day activities including being a part-time 'worker', a 'football coach', a 'house husband' and a 'father'. The modified roles he had created for himself brought meaning to his current life, thus enabling him to do 'being normal'.

There was however a double edged sword to this transition process; one that lay in Charles' recognition of difference and challenged the traditional roles of, for example, 'she cares, he provides' (Byng-Hall, 1995 p267). This is suggested in Charles' narrative of being unable to drive because of his epilepsy and his wife having to drive him around; a role which might usually involve the opposite dynamic. He felt a sense of guilt and feared at times that he had become *"a burden"* to his wife. He acknowledged how his activities would be curtailed if it was not for the emotional and practical efforts of his wife who willingly drove him everywhere. The inter-relatedness of stories that on the one hand promote successful identity transition and on the other hand depict dependency causes a shift in the sense of self wherein epilepsy is at risk of being foregrounded again (Paterson, 2001).

Charles' story again reflects the observations of Bury (1982) who spoke of this dependency in illness as disruptive, because the normal rules of reciprocity are breached. This is something writers of stigma have also noted. For example, at a societal level, Reidpath and colleagues (2005) observed that individuals with chronic illness appeared to have less social value than their healthy counterparts. It is also suggested that those individuals unable to engage in the process of reciprocal exchange because of ill health are deemed to have low social value and so are stigmatised (Reidpath et al., 2005; Allotey & Reidpath, 2007). At the level of the individual, Charmaz (1983) notes how such breaches in reciprocity may lead to a sense of being a burden which further discredits the affected person's sense of self (Charmaz, 1983). Reidpath and colleagues (2005) further extend their argument by proposing that societies stigmatise whole categories of people perceived to have poor social value, rather than individuals. Thus, simply having a chronic illness will automatically be accompanied by a loss in social value, even when for the individual concerned the course of the illness is benign and there is little accompanying functional loss.

In the next section I move from participant stories of present day concern about disruption to sense of self to examine expressions of change and uncertainty in relation to self and future.

6.2.4. Stories of disruption to future biography

Epilepsy and its limitations often prompted participants to reflect upon their lives to date as a means to informing their perspective on life in the future. These stories demonstrate a reading of life backwards (Becker, 1999) where the events selected are considered salient in their explanation of present and future time. Such stories brought to the fore the possibility of future disruption or losses; a biographical shift (Bury, 1982), where the perceived normal trajectory of a life diverges from what was expected. Two discrete story lines emerged in relation to disruption to future biography. The first story line, *'being stuck'*, reflects the apparent inability of two of my participants, Fran and Ricky, to move forward with their lives. The second story line, *'future change'*, reflects a sentiment expressed by a number of participants but explored here through the scenarios articulated by Brenda and Jessica. Examining the tensions that surround the creation of future continuity (or not) facilitates better understanding of how disruption is perceived and experienced.

6.2.4.1. Being stuck

> *"I wish somebody could make it go away".* (Fran).

Becker (1999) found that a period of limbo often followed a life disruption, before individuals could begin to restore a sense of continuity to their lives. In this regard both Fran and Ricky reported being *"stuck"*. Fran noted how it was difficult for her to *"move on"* because of the uncertain course of epilepsy:

> "*you'll be fine for months and then it will happen again and you think it's still there, the physical evidence of it* [seizures] *comes back and it's still there".*

Fran's inability to move forward with her life was articulated in stories that revealed what was at stake for her both socially and biologically (Kleinman et al., 1995); and the struggles she endured in trying to deal with her disrupted life - not least the worry she experienced in relation to her fear of seizure recurrence, which was a constant emotional burden. She spoke of the burden in relation to her children and the fear she experienced when she imagined them viewing one of her seizures. She felt that would be *"(…)frightening for them"* and she expressed concern about them *"being upset"*. She also spoke of her own fear of dying as a consequence of having a seizure:

> *"I'm absolutely terrified of having a fit. Whereas I was always frightened, feeling that I was going into a fit now I'm absolutely terrified, what if I died when I was having a fit and the boys were there? The whole thing just terrifies me".*

Her stories of fear of further seizures and the tension she experienced in managing her lifestyle, appeared to reflect Fran's propensity to ruminate on negative thoughts and actions that took over her daily life. According to Fran, *"having epilepsy"* was something she constantly thought about. Fran told of a life which was measured and organised; of the self-imposed social restrictions she employed as tactics to avert seizure occurrence, and of the subsequent guilt she felt about how her epilepsy impacted on the lives of her husband and her children. In this regard, Fran's accounts appear not so much about 'creating a sense of normality' but about managing and maintaining 'the appearance of being normal', guided by what she perceived as normative values of family life, and being a good wife and mother. In trying to maintain a sense of coherence, Fran acknowledged that clinically her seizures were well controlled. However, self-image and identity management was of paramount importance to Fran and she felt that as she got older, her ability to maintain the position of epilepsy as, *"a little secret you've got" was* becoming an ever increasing burden.

Fran's expressed emotional disruption to her sense of self, *"I would hate anyone to see me having a fit"*, including her own children – fuelled her efforts to keep up appearances, albeit she had not experienced a day-time seizure in the last 18 months. While the symptoms of Fran's epilepsy were less physically intrusive, the emotional burden of managing her condition and its potential intrusion on married and family life remained difficult for Fran to reconcile.

Similarly, Ricky too felt *"stuck in a rut". He was* unable to see a future for himself beyond the mundane, self-limiting strategies he employed in the daily management of his epilepsy. According to Ricky he was trapped in *"today"*; knowing that *"tomorrow will be just the same"*, he felt unable to move forward to the next phase of his life. The frequency of his seizures meant he was unable to work and when we met, Ricky was claiming long-term sickness benefit:

> "*I'm stuck in a rut…just going back to the hospital all the time, just waiting for them to try and find something out. To try and cure it. I just do the same things all the time"*.

In the hope that persistence would eventually pay off, Ricky spoke of his enduring participation in various anti-epileptic drug trials, in an attempt to find an acceptable route out of the disruption of epilepsy and to restore continuity to his life:

> *"He's* [consultant] *just put me on new tablets. As far as I know that's the only thing he said they can do. New tablets keep coming out all the time so all these new ones that come out he can add them to it and can put you on a trial for so long to see if they work. And all last year I tried a clinical trial thing and I had to like, every week they were taking blood samples. I don't really like needles so I even like suffered that even though I didn't like them. I have done a few different trial things and they have always come back the same. They haven't worked. They might have stopped it* [seizures] *for a bit but after about 3 months they've [seizures] gone back to the same"*.

This finding resonates with the work of Becker (1999) where the hope that persistence would prevent later regret was found to be central to decisions to use medical technologies. However, in this instance, the failure of medical technology to bring about positive change meant that, according to Ricky he was *"just stuck in a rut you just get used to over the years".* Like Fran, Ricky perceived his progression towards leading a 'normal' life as encumbered.

This state of stuckness or limbo, expressed in the narratives of both participants, can be likened to the typology of 'unadjusted adaption' identified by Schneider and Conrad (1981).

These researchers developed a model of adjustment in which they described a state of 'unadjusted adaptation' characterised by individuals being 'overwhelmed' by their condition, unable to make a positive adjustment, and where their sense of self was primarily as a person with epilepsy and all the negative connotations of that. One extreme sub-type of this unadjusted adaption is that of the 'debilitated', which Schneider and Conrad assert equates to the notion of 'master status'. This term, coined in the 1940's by Everett Hughes[14], I would argue can be applied to the circumstances of Fran and Ricky.

I also suggest this state of stuckness or limbo can be likened to the more dynamic notion of liminality (Van Gennep, 1960). In his work, *The Rites of Passage*, van Gennep explores the various stages in life crisis; namely, separation, merger or transition, and reincorporation. Liminal people are said to be stuck along their illness journey on the road between disruption and restoration of a sense of order to their lives. Thus, they find themselves suspended in social space, what Murphy and colleagues (1988) describe as having *"been declassified but not yet reclassified: they have died in their old status and are not yet born in a new one"* (p237).

The situations of Fran and Ricky demonstrate how individuals, after disruption, can often enter into a limbo-state for an extended period of time – liminal people tell the version of events they have told before. Thus we need to identify therapeutic and practical interventions that will aid adaption and enable individuals to see things differently; assisting in helping them to move forward from their old status in pursuit of alternative goals that are personally meaningful and attainable (Ormel et al., 1997a; 1997b). Furthermore, the liminal status of being stuck grounds the experience of illness in its embodied form. This is not only important in relation to the medical context but also to the social and political contexts in which that illness is experienced (Little et al., 1998). Here, the embodied suffering that ill health produces is brought to the fore, providing a deeper explication of the lived experience, which is important for understanding that experience and the processes and subsequent interpretation of adaption.

[14] Everett Cherrington Hughes, (1897-1983) was an American sociologist

6.2.4.2. Future change

As one example in relation to future change, Brenda's stories juxtaposed two scenarios that posed an ongoing sense of concern; both triggered by fear of change borne out of her embodied knowledge. The first scenario concerned a potential decline in her mental health. In Chapter Five, I noted that Brenda feared her condition might be more than epilepsy. She expressed concern for her future, "*It worries me because I think it could be early Alzheimer's*". Reflecting on her role as caregiver she continued:

> *"I know it* [epilepsy] *could do [progress to Alzheimer's disease] quite easily, because we've had cases like that. Erm…and the way that it's* [referring to her own condition] *not being controlled I wonder is it all epilepsy? Is there something else going on up there, you know"?*

Brenda's theorising that her epilepsy could be linked to Alzheimer's disease is not entirely without medical foundation: there is evidence to suggest that some degenerative disorders, such as, for example, Alzheimer's disease or pre-senile dementia are associated with epilepsy (Amatniek et al., 2006; Wilner, 2013). Concerned about the potential impact to her son of her receiving a diagnosis of Alzheimer's disease, Brenda declared:

> *"(…)well I'll be honest, I'd put a gun to me head or do something. Not for meself, I'd be happy daft, but for Peter* [Son]*, it would be awful, awful for him".*

The second of Brenda's concerns seemed, on first hearing, somewhat surprising – that was her concern related to "*cure*". This concern seemed to reflect a counter-story to those Brenda had told previously, where epilepsy intervention(s) (including undergoing brain surgery as a treatment to mitigate her seizures) focused on managing and alleviating symptoms with a view to returning to 'normal life'. However, Brenda's concerns around being cured highlighted tensions related to, on the one hand, her own experience in the roles of mother and worker and on the other hand, cultural-level normalising ideologies in relation to these roles. This, I argue, illustrates the holistic nature or embodiment of Brenda's epilepsy. She had absorbed epilepsy into her sense of self – it was not just about 'bodily knowledge' but about also the effects on her attitudes and on the meaning she placed on her everyday life, *"I don't know what it would be like living without epilepsy now(…)it would be a big step to be cured(…)I'd have to get used to not having it(…)".* The concept of a cure, while wished for by Brenda, also appeared to challenge her bodily experience and to alter what was known.

The difference to self that Brenda expressed in relation to the scenario of 'cure' stemmed from what must be relearned. In this sense a new disruption would likely emerge; the disruption of 'wellness'. Taylor (1993, p15) asserts, *"Being sick is one manner of being. That may not change by removing an epilepsy focus".* Being cured would lead Brenda into unknown terrain; a different social landscape upon which a new life must be built. Brenda wanted to change but also realised that in doing so she would have to make herself vulnerable; opening herself up to a form of discontinuity, a deviation from what she perceived to be her current 'normal' or tradition. Cure, for Brenda, would also bring along with it changed expectations of self and the undesirability of not being able to live up to those expectations, as well as in how she might be perceived by others now that she was *"well"* – raising the question - "*would they have greater expectations"* of her?

This finding resonates with the work of Wilson and colleagues (2001; 2004; 2007b) in which they discuss the concept of the 'burden of normality' and note that a need to acquire or prove one's normality can alter the balance of life. This constitutes major adjustment for people with epilepsy and members of their family, not least because patient and family expectations of how this 'normality' might be experienced span a range of psychosocial issues that vary in complexity in relation to the perceived effects of intractable seizures (Wilson et al., 2004). In attempting to achieve this normality, patients may over or under estimate what is required. Similarly, they may lack the necessary skills and abilities to achieve a new normality while no longer having the excuse of epilepsy to absolve them (Wilson et al., 2001). The broad psychosocial changes experienced by an individual as a consequence of the burden of normality, likely requires intervention(s) through an appropriate framework of rehabilitation (Wilson, 2007b).

A future change for Jessica related to the decision of whether to have children. In Chapter Five I noted that both Jessica and Fran expressed concern about the lack of relevant information and support they both felt they had received in relation to their medication at that time, the drug Epilim. Jessica once again re-iterated her concerns:

> *"…there is the risk to pregnancy and the fact that it* (Epilim) *could have a lot of implications birth wise and on any child…it was one of the higher risk medications*[15] *and I felt really frustrated because they'd* (healthcare team) *not told me"*

[15] 1-5% of women who take Epilim report vaginal infections, cramping or the absence of menstruation. Epilim has the potential to cause birth defects or spina bifida and is only recommended during pregnancy when there is no safe alternative. Accessed via: http://www.ehow.com/about_5454344_side-effects-epilim.html (Accessed 6th October, 2014).

In the face of her interpretation of previous events and experience, Jessica articulated concern about the role epilepsy might play in relation to risk to children she may have. For example, she articulated the risk of her children being born with a *"learning disability or a physical problem".* Jessica remained unsure. Reflecting on her uncertainty she said, *"Am I, or am I not going to have children?…I don't know".* Struggling to maintain selfhood in the face of this knowledge, Jessica also felt, as she got older, that her single status (she did not have a boyfriend when we met), also disadvantaged her. Being a single mum and having epilepsy would not, according to Jessica, *"be easy"*. Nor was it the scenario she had envisioned for her future self. This finding fits with those of Winterbottom (2012), who noted that some of the women in her study reported a decision not to have children because of fears that it was not possible to be both a mum and a person with epilepsy. Jessica realised the impact of her uncertainty about whether to have children on future life events; the potential loss of her social role as mother, *"I just think well, what with the seizures and the drugs, I just think it's* (having children) *probably too much risk".*

The uncertainty around motherhood (Winterbottom, 2012) and a decision not to have children (Crawford & Hudson, 2003) appear to be fairly common phenomena among women with epilepsy of childbearing age. In this example, we can see not only how disruption extends beyond the present to disrupt future stories of self (Travers & Lawler, 2008), but how also disruption encroaches on gendered identities. For example, as Bell (1988) and Riessman (2000) posit, such stories signal a tension around what it means to be a woman in a society in which narratives of being a woman are dominantly associated with motherhood.

6.3. New insights and other illness gains

The stories that follow might seem somewhat paradoxical in the sense that the experience of epilepsy appears to include both losses and gains. In fact, the majority of my participants, in one and the same accounts, juxtaposed emphasising the positive side(s) of their illness with expressing their despair in the face of their situation. In light of constraints faced by those coping with illness, Ormel et al (1997a; 1997b) argue that individuals seek to enhance their psychosocial well-being with the possible substitution of previous goals, activities, endowments and resources with close alternatives. This notion of substitution has the potential to counteract a long-term decrease in quality of life (Ormel et al., 1997a). Jacoby and colleagues (2014) note that, *"losses associated with developing a chronic condition such as epilepsy can be neutralised by replacement with valued others"* (p60).

Within the context of the current study, illness gains were described by a number of my participants as a consequence of the struggles they had experienced and the existential questions those struggles gave rise to. For example, Brenda noted, *"I wouldn't be as strong a person as I am now…accepting what is going on if it hadn't been for the epilepsy"*. She explained how she had "*worked through it. I think I've done well, I think I've done it the right way because you've got to learn by your mistakes"*

While epilepsy was seldom a predominantly positive experience, the stories that follow explore new insights gained in relation to family and social networks and for the role they played in creating continuity in the lives of participants and acting as a resource for coping with disruption.

6.3.1. The disruption of epilepsy: a platform for the demonstration of affection and support.

During a recent period of sickness Brenda reflected on how she had *"done a lot of thinking"*. This led to a re-evaluation and to a change in obligations in relation to life. Brenda recognised the new values in life she had created for herself:

> *"Yeah, well since I've been off sick the relationship with me son has been a lot closer, maybe because I'm not having the stress of coming from work. I mean as much as I love me job you still get stressed with it but also I'm giving more time to him, but also he can give me more time and err…like I was saying we sit down, eat a meal at the table coz we can talk and we know, he's old enough now to understand that it is good to talk. When I found out that there might be a chance of not being able to return to work I were dreading, how Peter* [son] *would take it because someone that's not working is living off benefits, you know? Anyway he seemed to be quite relieved that I'm not, going back to work because I feel that he does worry about me more than I've ever known".*

Previously, the physical burden Brenda's working life placed upon her wellbeing had left her unable to fully appreciate the everyday experiences she now shared with her son. Thus her perspective on life had shifted.

Having epilepsy had also prompted self-reflection on the part of Larry and Alan, concerning their relationships with others. Larry, for instance, drew friendship and comfort from the environment of the community care home in which he now resided. Reflecting on his previous hardships around family life, he concluded:

> *"I'm doing alright with these people in here; it's the best thing I ever did. It's a very supportive environment. Yes, yes, very supportive".*

Alan, speaking about his relationship with his parents, noted:

> *"(…)during the operation* [lobectomy] *we got a lot closer because me Mum wouldn't leave the hospital and they came in every day and just sat there and we did get a lot closer. My Dad came in and walked me down before they put me to sleep and held my hand and everything…I wasn't scared but I was, I was worried and I was thinking about things that I've not thought about before. What about if it doesn't go right, what about if I don't see my Mum and Dad again? And…it was quite upsetting and I could see my Dad was upset. I'll always remember his face when, just before I went to sleep and I could see a slight tear in his eye and I think I've only seen my Dad cry once in my life and I'll never forget that. My Mum and Dad have always been there for me. But through the operation and all this epilepsy they've been there for me a lot more and they understand that I had epilepsy but they don't treat me different".*

Alan's newly attained understanding in relation to his parent's demonstration of care and affection - previously interpreted by Alan as *"fussing"* -, led to an enhanced sense of what Alan regarded as important in his life. Previously Alan had taken these matters for granted, not fully appreciating the role his family played in his notions of normality.

6.3.2. Mediating the disruption of epilepsy: advocating for self and others

In considering the symptom-based stories articulated by Jessica in the early part of her narrative account (see Chapter Five for examples), my first thoughts were that these stories resonated with what Frank (1995) refers to as a 'chaos narrative' - stories defined by a body out of control, where there is no sense of order and no answers. However, when I reviewed these stories in context with others told, it became evident that Jessica's biographical work enabled her to strive for control of her health problems.

The early chaos stories of various healthcare encounters also highlight Jessica's attempts to demonstrate mastery over her epilepsy by constantly challenging medical orthodoxy. Like other participants in this study, Jessica described herself as taking action to gather information about her condition in order to inform her health decisions. Clearly information was perceived as a valued source of order and control (Kleinman, 1988) even if, according to a number of participants in this study, not always adequately forthcoming. In this sense, Jessica's stories also reflected her attitude and actions in managing the challenges of her epilepsy and depicted notions of a 'quest narrative' (Frank, 1995). Quest narratives embrace the belief that something is to be gained by this experience; and indeed, Jessica recounted a number of stories in the second part of her narrative that presented a strong message of identity and self-determination and positioned her as a person with epilepsy moving forward over time. This transition is depicted in a narrative

plot line where Jessica can be said to, *"enter as one kind of person and emerge altered in some essential way"* (Becker, 1999, p119). Specifically, Jessica moved from the position of 'reluctant participant' in her early stories of diagnosis, through 'information seeker', where she tells of how she sought out information on epilepsy to help understand her condition, to position herself as 'advocate for self and others'. She spoke of her *"hate"* of epilepsy being referred to as a disability:

> *"(…)when you get job forms and stuff like that and it says, do you class yourself as having a disability? I always put no. It was like NO!"*

Jessica reported a number of circumstances in which she felt compelled to take action by speaking up on behalf of both her and others; including the occasion she renewed her membership at the gym after a period of absence following the diagnosis of her epilepsy:

> *"I was doing the gym induction. I'd given him* [gym instructor] *letters from the nurse and one from the Consultant explaining about my particular condition. He said I would need supervision in case anything happened, then we're covered!"*

Jessica expressed her frustration:

> *"And I just went; I said you just haven't listened to what I said. My seizures are last thing at night and first thing in the morning; my epilepsy is well controlled and it's fine. I know myself; if I'm not feeling right then I won't get on the machine. Don't tell me that I've got to be watched, 'cause you're just treating everyone with epilepsy as if they all have an epileptic fit…And I think he* [gym instructor] *was like quite taken back that I dared to challenge him".*

On another occasion Jessica found herself speaking out at a health and safety event at her place of work:

> *"He said something about how people that have epilepsy always know when they are going to have an attack. And I turned round to him and I said that's not right. I said I can tell you from personal experience, and this was in a group of about 30 people, from personal experience, I have epilepsy, and from personal experience, you don't always know when you are going to have an attack and you are not necessarily okay afterwards. You might be confused; not a hundred percent with it. I said not everyone has an aura, some people say about a taste, some people say about smell, some people say they just don't feel right. But that's the problem with epilepsy; everyone gets labelled in the same way. And I found it absolutely amazing that this guy could speak about the health and safety of epilepsy and didn't know what might happen or could even say what epilepsy was! And as I said, I thought it was quite amazing that the guy doing health and safety, teaching people about epilepsy didn't even know what the condition was".*

Jessica went on to point out:

> *"(…)people are less educated about epilepsy as opposed to like I say, asthma or even you know diabetes or stuff like that. You don't tend to hear anything in the newspapers or media or anything like that. I never even knew Epilepsy Action existed! So he* [health and safety officer] *went on to say afterwards when he was at school they had a friend that had epilepsy, so he had some knowledge of it. But even his knowledge of it still had some elements of stereotyping in it. And he was sort of like what would you do and I gave him like a leaflet afterwards. I said does it worry you? And he was like well, yeah because I would want to make sure things were all right. And I can see that he was genuine about what he was saying but beforehand I, I always thought of it from my perspective as opposed to the person who would have to deal with it there and then. So I guess in that sense he made me more aware of someone else's thoughts about it".*

Anspach (1979) labels the adopted position of advocate as one of *"identity politics",* describing those who advocate as *"politicised deviants, collectively engaged in attempts to reweave the fabric of identity".* While this study focused on stigma and political activism in relation to patients suffering physical and mental health issues, the notion of identity politics can be applied to other stigmatising conditions such as epilepsy. Anspach (1979) argues that the purpose of identity politics is to contest predominant imagery in an effort to change both the self-concept of the individual and societal conceptions of the (stigmatised) 'group' to which they belong – in the context of this study, people with epilepsy. The notion of identity politics captures the idea that much of what may be considered as a personal problem is rooted in social and political issues and can only be addressed through social and political change – in the context of Jessica's account a call for public information and education around the condition of epilepsy that is more high profile. Identity politics as applied to epilepsy demands that society view people with epilepsy as:

> *"(…)active, viable, strong participants in society who are different because of their seizures but not less than full members of the human race".* (Dell, 1986 p204).

This striving for humanness can itself be health bestowing (Anspach, 1979), and the stories of Jessica demonstrate how disruption and attempts to create continuity, promote agency, resistance and power (Becker, 1999).

6.3.3. Epiphany narrative: "I had the surgery then I changed"

One final story line was offered by Alan, Ashley, Karen and Brenda, who had all undergone surgery for treatment of their seizures; these stories were all characterised by their narrators' 'epiphany of change' in relation to sense of self and circumstance. Interestingly, none of these four participants had attained complete post-operative seizure remission,

though for Alan, Ashley and Karen, their seizure severity and frequency had been significantly reduced. The successful medical management of seizure frequency and severity has been found to positively impact on an individual's quality of life (Jacoby, 1992; Jacoby et al., 1996; Jacoby et al., 2011) and here, all three participants positioned themselves post-operatively as former epilepsy patients.

These participants were keen to emphasise the difference in their symptoms and in their lifestyles between *"now"* and *"before"*. Alan pointed out the normality of occasional *"anxiety attacks" (…even me Dad has them…*), for these were "*nothing"* in comparison to epilepsy – *"anxiety attacks are nothing to be honest…anxiety attacks are weak; epilepsy is strong".* Alan emphasised that now one of his future goals was to negotiate greater independence for himself which he intended to achieve by showing his parents that he could behave responsibly; they could trust him *"now"* to make his own decisions about how to manage his life.

Ashley also noted that all she experienced now was*, "just these little feelings, as if I'm going to go into a small seizure but I don't thank God. They mostly pass me by".* A reduction in the severity and frequency of Ashley's seizures meant she was now able to *"just keep looking forward". She told me, "I don't look for any anxieties or fears. I just look forward and hope that things will get better all the time, whereas before I would have looked backward"*

Karen too noted that over the previous year her *"life just changed".* She referred to long-term sickness benefit to highlight how difficult the situation was before. Now she drew a renewed picture of employment, *"(…)my life just changed, I wanted to help people, so I run an epilepsy club on South Road* [road name changed]*"*. This envisioned future for herself was in contrast to her earlier thoughts of the inevitability of long-term sickness benefit and early retirement on the grounds of ill health.

These participants had begun to establish and experience new routines after a long period of disruption. However, this recognition of positive change to sense of self was also evident in the narrative of Brenda. Although she did not perceive her surgical outcome as a positive one (she reported her seizures as becoming more frequent and less predictable), she felt she had experienced a positive change in relation to her sense of self which played out in the decision making that had underpinned her surgical experience:

"I felt I had to do it, I have to do it to see if it does work, but also when I'd done it I felt I'd achieved something, actually doing it"

6. 4. Conclusion

Frank (1993) maintains that illness narratives always contain some reference to *"the 'new' person that illness has produced out of the old self"* (p40). Surprisingly little analytic attention has been afforded to personal narratives of people with epilepsy where "*biographical reflection"* or "*biographical reconstruction"* (Carricaburu & Pierret, 1995) is likely to occur against a backdrop of potentially disruptive events and experiences. Such themes were kept in mind in this analysis – a comparison of which has been used to highlight the theoretical and practical implications of the heterogeneous experience of epilepsy.

In the present study, many of the stories told about living a life with epilepsy echo Bury's (1982) contention that the experience of illness, especially when chronic, disrupts the structures of everyday life and the forms of knowledge which underpin them. I consider one of the most significant findings in this study to be that, in the main, my participants' narratives did not include the notion of immediate, dramatic identity change at the point of diagnosis of their epilepsy. This is contrary to findings in earlier stories and models of illness narratives; including, for example, Price's (1994) narrative about feeling as if his pre-illness self had died when he fell ill, the collective narratives of prostate cancer survivors (Korder, 1997) and the collective narratives of patients with chronic fatigue syndrome and fibromyalgia (Strauman, 1997; Asbring, 2001). For the majority of my participants there was 'hiddenness' to epilepsy. Participants recognised that hearing a diagnosis of epilepsy meant that something had changed, but in the main a realisation of the meaning of that change was not evident or articulated until they re-situated themselves within the various contexts in which they attempted to live.

I have shown that over time the accompanying illness experience and biographical disruption involved both illness losses and gains that had consequences for identity and social functioning. This is consistent with other earlier chronic illness studies (Charmaz, 1991; Ormel et al., 1997a; 1997b; Asbring, 2001) and more recently, and more specifically, in relation to epilepsy research (Jacoby et al., 2014). In addition, participants within this study group demonstrated the potential for the concept of 'loss of self' (Charmas, 1983) to evolve as a concept of loss of ***selves.*** Theoretically, it can be argued that people with

epilepsy are continually redefining self in response to not one but several 'critical incidents' (Giddens, 1979), since epilepsy potentially not only represents a single critical event but multiple critical events, as a consequence of recurrent seizures.

The stories told throughout the journey of life with epilepsy, demonstrated that a process of coming to terms with the condition had in some way been started by all but two of my participants: Fran and Ricky. For both, their status of 'unadjusted adaption' (Schneider & Conrad, 1981), was characterised by their sense of being overwhelmed by epilepsy. The consequence of unadjustment was one of becoming stuck; a liminal state (Murphy et al., 1988; Little et al., 1998) in which their daily routines of self-limiting strategies to manage and mitigate the symptoms of their condition prevented them from moving forward with their lives. Previous quantitative research indicates that people with epilepsy, where seizures were in remission or well controlled reported a quality of life that mirrored the general population (Jacoby, 1992; Jacoby et al., 1996; Jacoby et al., 2011). Thus, seizure control appears to be a key facilitator of loss reduction in the promotion of psychosocial wellbeing. However as my participants' stories attest - including Fran, who on her own admission, had been day-time seizure free for 18 months – seizure remission would appear to be only one of a number of influences on disrupted biographies.

Other participants' stories of loss and adjustment (albeit partial) across the sample indicate the potential large difference in the degree of perceived disruption and subsequent reconciliation. As an example, the disruption of epilepsy for Yolande, Larry and Martin appeared to take its place amid other compelling concerns including tensions within relationships, economic burdens and other co-morbid conditions, serving to demonstrate the importance of context (Williams, 2000; Faircloth et al., 2004), as individuals attempt to reconcile the loss of valued aspects of their lives. Participant's stories also highlighted that reconciliation (partial or total) may occur in relation to one aspect of an individuals' life, while epilepsy remained salient in another or other aspect(s) of the same individual's life; an indication that a positive transformation of identity may be partial rather than total, and is not always sustainable across the trajectory of the condition; again highlighting the contextual and relational nature of epilepsy.

Disruption prompts a process of rethinking about what is meaningful in life (Becker, 1999). Restoration of meaning to life requires transformation - the creation of order out of disorder, even though order may not be continually achieved. In striving for continuity and

a restored sense of normality some participants told stories of their ability to accept their situation and to *"battle through"*, while other stories positioned family, friends and employers as having a role to play in facilitating practical and emotional support and adjustment. The multiple ways in which participants attempted to do this reflected their creative use of personal, family and social resources.

However, it is also evident from these stories, that much remains to be done from a health and social care perspective to assist individuals to move forward in a positive way, and to minimise the effects of epilepsy on the overall functioning of the individual with the condition and their significant others. Such interventions require a multifaceted, multidisciplinary approach to assist people with epilepsy to identify new and appropriate goals to neutralise the negative effects of the condition - both medical and psychosocial - and to promote a sense of normality. In this regard, the strength of narrative accounts lie in their ability to illuminate the process of change that individuals go through, which is critical if appropriate support is to be offered.

CHAPTER SEVEN

7. Living with epilepsy: stories of undesired difference and stigma

7.1. Introduction

In Chapter Three I set out the historical, cultural, medical and social constructions of epilepsy and their implications for the notion of stigma. Some fundamental debates about the stigma of epilepsy were introduced. The vestiges of cultural taboos and fears, attributed to beliefs about epilepsy as demonic possession or divine punishment (Tempkin, 1971), the negative reactions of others to witnessing sudden loss of motor control, shaking and incontinence, and to epilepsy's association with varying degrees of mental health issues has resulted in epilepsy becoming a stigmatising disorder *par excellence* (Vaccarella, 2011). Indeed, discrimination and prejudice towards people with epilepsy are still evident worldwide (Anonymous, 1997; GCAE, 2003; 2004; Snape et al., 2005). An appreciation of these debates around the attribution of stigma is important as stigma remains a major issue for people with epilepsy (McLin & de Boer, 1995; Jacoby et al., 2005b) and arguably a more pressing problem than the management of its clinical course (Jacoby & Baker, 2000). While seizure control (which encompasses: seizure severity, frequency, and efficacy and tolerability of anti-epileptic drug treatment) is the overriding focus of treatment, it is essential to remain mindful of the importance that people with epilepsy place on other dimensions of daily functioning including the issue of stigma (Sander, 2005).

It is helpful at this stage to revisit the work of American sociologist Erving Goffman (1963), whose contribution to the understanding of stigma can hardly be overstated. Goffman argues that stigma is best explained by reference to the notion of deviance[16], for example, deviation from prevalent or valued norms. He also demonstrates that deviance is not an inherent characteristic, rather a person is not a deviant until his acts or attributes are

[16] Parsons (1991) argued the link (analytically) between illness and crime as both representing a threat to effective role performance and as being 'dysfunctional' for society; calling for appropriate interventions of social control. Dingwall (1976) advocated a phenomenological, insider's approach to illness as lived experience. He suggested that illness might be considered deviance (a) to the extent that it involves behaviour perceived by others as 'out of the ordinary' or unusual, and (b) if sufficient intentionality or wilfulness can be attributed to the ill/deviant actor for the conduct in question.

perceived as negatively different. In this regard, it can be argued that seizures, which can range from the indiscernible (absences) to the dramatic (tonic-clonic convulsions), constitute violations of taken-for-granted expectations about the competence of actors (in this context, people with epilepsy) in social settings; as such they are likely characteristics of deviant behaviour (Schneider & Conrad, 1980). The observation by one of my participants, Martin, makes this point emphatically clear:

> *"No they* [members of the public] *don't understand, they don't understand. They believe that man has epilepsy; watch him. He may have a fit, there and then! You have got to keep watching him all the time, like. People don't see that, people just see a black and white picture, if you're down as epileptic then you're epileptic and you're going to have a fit at any minute. That's how the public see it, they don't see me sitting here talking to you about it, they think any second now he's going to flop over and have a fit. They just see that sort of thing; they don't see me as erm…as a normal person".*

The moral parallel between illness and deviance is well recognised in the sociological literature. While Schneider and Conrad, (1980) assert that having epilepsy is not necessarily considered to be 'deviant', it seems clear that it is frequently defined as stigma, from both the perspectives of those who stigmatise and of those who suffer from the condition (Schneider & Conrad, 1980; Scambler & Hopkins, 1986; Scambler, 1989; Jacoby, 1994; Baker et al., 1999; 2002; Baskind & Birbeck, 2005; Jacoby et al., 2005a, 2005b, 2008; Jacoby & Austin 2007; Fernandes et al., 2011).

Goffman (1963) defined the term 'stigma' as referring to an attribute that is 'deeply discrediting', allowing the stigmatised individual to be viewed by society as 'not quite human'. The relevance of this definition of stigma to epilepsy has previously been established within the context of this work (see Chapter Three, section 3.4.); as a condition across cultures and across time, epilepsy has almost universally been defined as 'undesired difference' (Temkin, 1971). The social stigma attached to epilepsy and having seizures carries a number of distressing consequences; including, for example, effects on mood, self-esteem and behaviour (Collings, 1990; Jacoby, 2002). Stigma has also been found to have a negative effect on interpersonal relationships, general health, education, employment and overall quality of life (Gallhoffer, 1984; Ratsepp et al., 2000; Austin et al., 2002; Jacoby, 2002; Jacoby et al., 2005a). Indeed, the 'halo effect' of the subjective experience of a person with epilepsy, emphasises that epilepsy is so invasive to the life of the individual that its influence is felt in all life domains (Amir et al., 1999). As Martin noted:

> *"There is no known cure for epilepsy, and the way that I see it, epilepsy has taken a part of your life away. That's the way I perceive it because it is withdrawing part of your life. There are things that yer can't do. I believe it is taking part of your life away, it's like nibbling a piece of your brain and then that's a piece of your life gone".*

Fran, speaking of the impact epilepsy placed on her quality of life explained:

> *"I just think, as I say, its guilt all the time, guilt you know over the boys and guilt that we can't even go out and enjoy ourselves, I can't drink and we've always got to be home by a certain time and everything is coloured by it* [the perceived risk of having a seizure]. *Everything that we do, going on holiday or anything, everything is just you know, oh well we're going to have to go home, and I just feel constantly guilty. And he* [husband] *doesn't make me feel that way but I feel that way, I feel that it affects the whole family. As I say, even though it is a condition that I have and it* [having a seizure] *doesn't happen that often it affects me hugely, you know, in so many other ways. I mean when you approached me and I thought, my God maybe other people feel the same way that I do. Because I've never, I've never ever spoken to anybody about my epilepsy. And even friends and things nobody, you just feel that nobody understands how you feel".*

In Goffman's analysis (1963), an individual with a stigma is said to be either discredited, which means they are different in a visible or known way to others, or discreditable, which involves having a deviancy that is not clear to see or understand. However, a stigma begins with the acceptance of a stigmatised identity produced by the reaction of others (Kleinman, 1988) to one's condition. In relation to epilepsy, Scambler and Hopkins (1986) explored the reactions, experiences, and coping strategies of people with this condition, from which they proposed a 'hidden distress' model. Episodes of stigma can be described as 'enacted' or 'felt' (Scambler & Hopkins, 1986; Jacoby, 1994). Enacted stigma refers to the occurrence of discrimination solely on the grounds of the individual's social unacceptability (excluding episodes of legitimate stigma such as exclusion from driving and certain occupations on the grounds of safety to self and others); felt stigma is often more multi-faceted and refers to fear of enacted stigma and the shame associated with being a person with epilepsy. Shame derives from an individual's perception that having epilepsy is a transgression from the norms of identity or being (Goffman, 1963). Scambler and Hopkins (1986) proposed that following diagnosis adults with epilepsy generate an acute sense of felt stigma even before any exposure to enacted stigma, and that as a function of successful concealment, felt stigma typically proves more disruptive to the lives of individuals than enacted stigma.

In a previous co-authored paper (Fernandes et al., 2011), I considered findings from this study in relation to: the nature of 'difference' as experienced by people with epilepsy, how

that difference translated into stigma, and how epilepsy stigma might be addressed through targeted interventions. In this chapter, I once again draw on the detailed accounts of my participants to revisit such considerations in greater depth as a means to exploring and understanding how stigma among people with epilepsy in this study was played out.

7.2. Epilepsy narratives and stigma

Much has been written about the beliefs, attitudes and experiences of people with epilepsy (see Scambler, 1989 for a classic account). If we accept that experiences of epilepsy have been influenced by perceptions of negative difference, ie. deviance, and their elicitation of adverse responses, ie. stigma, then stories which say something about the meaning of living with epilepsy necessarily also say something about deviance and stigma. The epilepsy narratives offered by my participants provide support for earlier theories related to stigma. In particular, their stories confirm the stigma that a disease label carries with it (Arnston & Drodge, 1987; Sontag, 1990; Whyte, 1991). It can be observed in participants' stories (as told in chapters five and six) that the term 'epilepsy' embodied a collection of legal and social restrictions. For example, participants acknowledged their diminished abilities in relation to employment and driving. Stuart reflected:

> *"I started having more frequent attacks, especially watching bright colours and things like that. Unfortunately I started an apprenticeship by then, at 16, I was an engineer. So it did hamper me training, especially on the machines, and it seemed to affect me life in that, in jobs, I have to go picking me jobs. Couldn't let me drive, so I went back into engineering, a different side of the machines".*

> *"For years when I was younger 18, 19, 20 I was ashamed. I…you didn't like to tell people. You didn't like to tell people about it. You kept it hidden. You know, just amongst your family, and close friends and that's why it felt as though it's, you known a stigma on you, cause you know, everybody you know, 19, 20, has had to take driving lessons and all that and you couldn't do it. And it used to worry me".*

Jessica had relinquished her driving licence following her epilepsy diagnosis and revealed her views of the way such legal restrictions had impacted upon her life:

> *"(…)one of the things that I was saying like it's this thing that erm…you know people automatically assume these days that you drive a car. And everyone has a driving licence and you're sort of our age and you don't. It's erm…particularly hard when it comes to relationships because you then sort of have to make up an excuse why you're not driving - almost cover up, or you have to say well it's because I've got epilepsy. Then it's like you don't want to share that with someone you're only just starting to get to know. So I found that really hard but luckily now I am back on the road, touch wood, which is great practically but more so because it's like coming back to normality'.*

We can discern from the above comments not only how being unable to drive can be stigmatising in its own right, but also how driving appeared to be a symbol of a valued self, in terms of one's ability to maintain or return to a normal life. Continuity in the lives of these participants was a casualty of having nominal control over their body and the loss of the ability to drive appeared to prompt the realisation that life was becoming restricted.

Participant stories also demonstrated the self-sustaining nature of epilepsy stigma and, as a consequence of this, the durable nature of a spoiled identity. Although all but two of my participants (Fran and Ricky), were variously coming to terms with their condition, all came to recognise that they would probably never be cured; and that if the condition is not curable, only controllable, the propensity for seizures was ever present. As such, the threat of a contaminated identity (Goffman, 1963) also remained ever present – *"I mean, I'm saying that because I can get on a bus tomorrow and I might have a fit, I'm saying that's not normal, not a normal thing to do"* (Martin). In this regard, participants could never return to being the same person they were prior to their diagnosis. The uncertainty that surrounded seizure occurrence and its consequence(s) was, for the majority of participants, a recurring reminder of their epilepsy identity.

7.3. Personal strategies to handle stigma

It was noted in Chapter Six that viewing oneself as different to normal not only carried the potential to be disruptive, but also of arousing sentiments of felt stigma and anticipated rejection. Participants recognised that often this entailed feeling anxious about the possibility of enacted stigma; a sentiment heard within a number of stories. For example, Alan spoke of his seizures as *"not frightening*" to (him)self rather, he *"worried"* because he didn't know when his seizures were going to happen or if a seizure were to occur in public, what others might think of him:

> *"I was always on edge that it [seizure] was going to happen at school and what people would think of me then…but I wasn't bothered about having attacks at home, coz they've* [family members] *seen me have attacks. When I was at school it was a different situation. So I wasn't frightened, I wasn't scared or anything coz it's not like me to get scared about that type of thing, I'm a strong person inside but I was worried what people would think".*

> *"I didn't want them to like think I was a weirdo and turn on me and think 'Oh he's a freak because he's got epilepsy'*

Perhaps as a means of neutralising his fear of enacted stigma, Alan's comments appear to be dominated by what Bury (2001, p28) terms the 'moral' aspect of illness narratives, which refers to strategies for affirming a sense of self and social identity, in Alan's case as a *"strong person".*

As noted earlier, the comments of my participants suggest the label of epilepsy still retains powerful negative connotations. Participants spoke of the notion of epilepsy as being *"unclean"* and likened it historically to the "*plague", the* "*voodoo dolls and Africa"* and "*bloody witches".* Negative connotations of epilepsy also played out as a consequence of association labelling, that when applied to an individual can *'spoil'* their identity (Goffman, 1963). The adjectives*: "schizo", "freak", "weirdo", "mad", "deranged", "druggy", "drunk", "skiver",* were articulated by participants as a means of expressing their uncertainty and fear in relation to how others may perceive them as a consequence of their epilepsy symptomology, which was often outside their control. Such appellations can reinforce an association between disability, evil and abnormality (Conrad & Schneider, 1992). This lack of understanding and knowledge among others about what epilepsy is was constructed by participants as being a source of potentially negative reactions. The following comment, offered by Stuart, illustrates the pervasiveness of such labelling:

> *"Everybody used to look on it as a joke; if you understand nastiness you will know what I mean so I hid it (epilepsy) to meself, you know, and didn't communicate it. So I haven't, didn't do a lot of things for years".*

This finding is consistent with the earlier work (Schneider & Conrad, 1980; Scambler, 1989) and illustrates that the use of pejorative labels has potential to impact negatively on an individual's sense of self, and as a consequence perceptions of felt stigma likely hide a person's true identity (Fernandes et al., 2011). This highlights the need for care to extend beyond the focus on seizure control to addressing freedom from fear of the psychosocial affronts associated with having epilepsy. It also raises the importance of the provision of correctly framed public attitude and information campaigns concerning the condition, as a means to correcting information deficits and improving public behaviour toward people with epilepsy (Jilek-Aall et al., 1997; The Epilepsy Foundation, 2004; Snape et al., 2009). Such interventions would help to place people with epilepsy into a more positive perspective.

Returning to the current study, participants clearly perceived the social meanings attached to having epilepsy and seizures as a threat to their status as normal and competent

members of society – what Scambler (2004) refers to as an '*ontological deficit'*, wherein his research participants '*felt imperfect beings'* who were not or did not feel as they should (p31). As Brenda articulated, "(…)*I just feel like I'm not, not able to do the things that I should be able, that I expect to do…able to do what everybody else does".* Theoretically, Link (1987) argues that it takes power to stigmatise; those perceived as undesirably different are the end products of a stigma process in which such difference is labelled as socially important and associated with negative stereotypes. Individuals labelled as such face status loss and discrimination and find themselves disempowered (Kai & Crossland, 2001).

My participant's stories demonstrate that in responding to the potential risk of a spoiled identity, individuals continually strove to be regarded as fully-fledged members of society - such efforts themselves often engendering further disruption to participants' sense of self. In this regard, there was the need for participants to constantly re-negotiate their social position in order to seek legitimisation (Bury, 1991). The notion of stigma thus became a powerful mediating framework for personal action and social involvement, where a number of strategies to avoid being exposed to enacted stigma were developed and set in place by participants.

The coping responses set in place by my participants resonate with the findings of earlier work conducted by Link and colleagues (1989). Although the clinical focus of Link's work was on mental ill health, his findings are transferable and have relevance for the stigma associated with epilepsy. Link et al's theory proposes that the more an individual believes that they will be devalued and discriminated against, the more they feel threatened by interacting with others. As a consequence they may keep treatment a secret, they may try to educate others about their situation, and they may withdraw from others they perceive as potentially rejecting. These strategies can lead to negative consequences for social support networks, jobs and self-esteem. Link and colleagues reported that respondents endorsed strategies of secrecy, withdrawal and education of others to cope with the threat they perceived to self.

Similarly, the coping responses adopted by participants in the current study to deal with their perceived stigmatised status, were situational and involved for example, distancing oneself from others, concealing epilepsy, and managing information about their condition (Schneider & Conrad, 1988; Link et al., 1989). My participants' stories about setting such

strategies in place highlighted how they developed both a relational sense of self and an image of a self continually at risk. These stories are explored in greater detail below.

7.3.1. Distancing oneself from others

A number of my participants, (Alan, Brenda, Fran, Ashley, Martin, Larry, Ricky and June) spoke of how they had withdrawn (albeit to varying degrees and as either an intermittent or an enduring strategy) from areas of their social life. This withdrawal was described in two ways, first as a means to avoid the expectations and demands of others; and second as a moral activity. The first strategy, avoiding the expectations and demands of others in relation to how one ought to behave, included avoiding people or situations where negative attitudes had previously been encountered, in order to avoid being exposed to enacted stigma. For example, the post-operative scar resulting from Alan's brain surgery acted as a kind of stigmata or 'mark' (Weiner et al., 1988) and he was subjected to bullying by his school peers. As a consequence, Alan moved from his earlier social world and withdrew to the confines of his own home:

> *"When all the bullying started and all the names started, I felt like an outsider so I stopped going out as much because I just felt like an outsider straight away. In my eyes I was an outsider and I didn't like it. So I just, I just stayed in all the time and that's when, like people just basically forgot about me. I wanted to go out more, but I didn't have close friends to go out with. Except for one friend but he came round here. We never went out, he came round here. I just hid away, you know"?*

As a further example, June commented on how you, "*don't know what you've said or done"*; but by withdrawing and *"sticking to what you know"*, she appeared to live within a shrinking world. She explained:

> *"Even me sisters, they always say don't worry about it, but they keep well away. I think it frightens them a bit and they don't know what to do when I take one* [have a seizure]".

The second strategy of withdrawal was one of moral activity which positioned the narrator – again, in this example, June - as protective towards others, *"I've restricted me from them…I keep away in case I take a blackout".* She continued:

> *"It's embarrassing for people, because I'm just more or less standing there or staring at them and there is nothing they can do and they are frightened. I think it is embarrassment with most people because they don't know what to do, there's nothing they can do until I come round".*

June's perception that her symptoms created potential embarrassment for others and her concern that she felt *"an embarrassment to people",* led her to reconsider her lifestyle. She told stories of her efforts to cope with *"being epileptic"* in her previous roles of wife and mother and of her traumatic experiences as a consequence of *"suffering with blackouts":*

> *"I'd walk over the road in front of cars and buses and me mind 'ed blackout. I'd come round to find the drivers screaming at me; stupid bitch, why don't you look where you are going".*

Such historical stories provided the context for newer ones in which June explained and morally justified her decision to withdraw from social activities:

> *"I'm not the type of person who will go out now, as I told you, I keep myself very much to myself and I don't like going out…and I don't bother with the neighbours too much in case I take a blackout and they don't know what to do. It's an embarrassment for people because I don't know I'm going to take one. I can't say, 'I'm going to take a blackout in a minute' because I don't know when I'm going to have one and I can't apologise to them beforehand so they're left with me, ya know, just staring at them. So I keep away. I feel safer in my own home because I won't put anyone into an embarrassment if I take one".*

June's present experience appeared to differ greatly from her past. She told of how now she read a lot and worried less, as being by herself meant she had little to worry about. In claiming this time for herself June spoke of how she had routinised her daily accomplishments – her morning trip to the shops, caring for Birdie her parakeet, lunch, afternoon reading, evening meal, and her medication ritual: *"…always after meals. I treat it as my second course so I don't forget",* to enable her to better cope with the contingencies of everyday life.

The greater the potential embarrassment from the unpredictability of seizures, the more likely one's self-concept is at risk, and as Goffman (1963) suggests the individual will restrict his or her life voluntarily. Such voluntary restrictions to socialisation were also articulated by other participants, for example Karen:

> *"I don't keep in contact with any friends, so it's just purely, me, myself, I've a friend who I can ring or whatever, she rings me erm…and that is it. If I go out for a drink, I don't much nowadays anyway as there's only a few bars which you can go into without feeling I'm being looked upon at everything you do, erm…but I am a very lonesome person. Just me; myself".* (Karen).

A number of participants compensated for this kind of social withdrawal by developing closeness with others who they could *"trust"* or who they felt were able to *"understand"*.

In this regard those perceived as offering the greatest support became key characters in the stories they told. For example, Alan continually acknowledged the support he received from both his parents and his girlfriend, Brenda's brother was a *"rock"* and she did not know what she would do without the constant support of her son. Fran noted that her husband was *"(…)the only one that really seems to understand",* and Charles and Stuart were cognisant of the practical and emotional support each received from their respective wives. Practical and emotional support was also spoken of by Jessica in relation to her parents, June in relation to her gentleman friend, by Ashley about her mum and her daughter, and by Larry in relation to the friends he had made within the community care home in which he lived. This situation appeared to place those with epilepsy in a kind of 'in-between' world where family and close friends, for instance, knew and understood about their condition and acted as a social buffer; lessening the burden of epilepsy where possible.

For some participants however, there was a double significance to developing closeness with others. Trust and understanding enabled the 'chosen others' to be perceived by participants as sympathetically attuned human beings from whom participants drew help and support. However, these very characteristics, on occasion, prompted participants to express negative feelings about the same 'chosen others'. Attributes of understanding and support inevitably also fostered concern, which on occasion was expressed by some participants as being seen as *"over-protective"* or *"being made a fuss of"*. These experiences were commonly reported as protective measures which were sometimes perceived as impositions of over-protectiveness rather than support. As Jessica reflected:

> *"I had to, I remember going into town to do some shopping and everyone's going I'll take you, I'll do that, I'll get it for you and I was like just let me do it and erm…I just, I was just getting really frustrated coz they thought I was unable to do stuff. There was no routine to my life and no normality".*

Consistent with the findings of Schneider (1988), eliciting too much concern from others was seen as an assault on one's independence and contributed to perceptions of self as being less than fully able. Alan, as another example, identified *"greater independence*" as a future life goal. He intended to achieve this by demonstrating to his parents that he could behave responsibly, and that they could trust him to make his own decisions about how to manage his life.

7.3.2. Concealing epilepsy

Consistent with the findings of previous researchers (Schneider & Conrad, 1981; Scambler, 1989; Westbrook et al., 1992) many participants in this study chose to keep their epilepsy a secret when and where possible. The sporadic, nature of seizures meant that this could be achieved by concealment. This involved maintaining a façade and was identified by some participants as a key strategy for self-presentation in relation to the expectations of others.

As an example, Jessica explained that:

> *"I wouldn't get the tablets* [her anti-epileptic medication] *out in front of people. God, this one time there were so many people and then there was like all these people around so I just like took it quick gone! I just, I think with me, I don't know if it's me being self-conscious or just conscious of the fact that people may start asking questions and I just think, it's like, if they're people that need to know, I'll tell them, but if it's strangers, I feel like they'll start asking questions and I don't want to give them an explanation? And then if I decide to tell people, whether like I say, it be a friendship or a relationship, I can choose to tell them how much, and to what extent it's affected me, in which case I try to keep it to as very little as possible".*

By minimising the potential for negative judgements by others about their condition, concealment was an adaption strategy that assisted participants in maintaining their earlier identity. 'Passing' or impression management (Goffman, 1963) was particularly evident in the descriptions of Stuart, Larry and Karen in relation to concealment of their epilepsy from employers; and, in the case of Stuart and Larry, in their subsequent attempts to retain their identities as worker and breadwinner for their families. As an example, Stuart explained:

> *"I didn't disclose the epilepsy, because I was frightened…what I mean is, at the time I was young and I had a young family I didn't know if I would be out of work. I just wanted to work and I felt if I disclosed it [having epilepsy], well it's just that if two or three people are going for a job and there was one with epilepsy and one or two was alright and there was two jobs, the fella who was alright would get it and you wouldn't get it. And I had applied for jobs in the past and disclosed it and just got told that because of your epilepsy? I just didn't feel it was worth disclosing. I never felt guilty because I got the job, and eh I ended staying there for over 25 years! I thought if I take me medication I'll be alright! Mind you, you can take the medication and still have the attacks [laughs]. But in the end the seizures were more frequent and they [work] found out. They were very good about it, let me see the doctor and used to get paid when I went to see the doctor, but the law had changed by then and there was less discrimination".*

Although pretending to be normal (either by choice or by duress) appeared at the time to be a promising strategy for those participants who adopted it, their stories revealed how difficult it was for them to live as a person who did not have epilepsy when they actually

did. For example, according to Karen, she had always been a keen squash player and a very competitive person, *"(…)it's that urge of needing to win and wanting, well wanting to win"* . She was keen therefore, to impress her boss when he discovered their shared interest in playing squash:

> *"He* [Boss] *said, 'do you want a game'? And it was great playing with him because it was me playing him around so it was him who used to get a sweat on and we came off court this one time and I thought whoops, Oh no!, Here we go again. I had to make an excuse to leave quickly, coz its after playing squash, that'll bring on fits as well. I never told them* [work] *about epilepsy, and I couldn't let him see me fitting. And I thought thank goodness for that".*

We can see from Karen's recounted experience that concealment, or to use Goffman's (1963) term, passing, was rarely an enduring option whereas becoming *discredited* (Goffman, 1963) was an ever present risk to maintaining a valued self. Once adopted, the strategy of concealment often created additional difficulties in the lives of participants. It was a strategy which proved to be both physically and emotionally demanding as individuals strove to maintain control over situations in order to keep the symptoms of their epilepsy 'hidden' and not to let information about their condition leak out. Success in this endeavour could not always be taken for granted. Returning to Karen, she went on to explain that on another occasion:

> *"I was still having an aura, a couple of minutes warning for the aura(…)so I just went into the ladies toilet, locked the door. Sat on the toilet seat and I thought right okay here we go and I was, you know, had the aura coming on and erm…I remember slobbering, waking up to slobbering and then I was passing water in fits, it only happened a few times, it wasn't constant thank goodness, it was just a few times and I remember waking up with this saliva and looking up and my boss, his head was over the top of the toilet. Coz there were toilets on both sides, and his head was over the top, and there were a few other people around trying to get in. You know a sea of faces and the main boss, great! That was the first time I'd had a fit with them* [work colleagues] *around and so from that fit onwards everyone was aware that I had fits. Then there was all the form filling* [required by the occupational health department at Karen's place of work]*. I didn't really accept it coz I, I was embarrassed at having fits, always have been. So that's how they found out".*

Concealment, especially within the boundaries of one's own home was especially difficult. Fran, for example, found this practice an ever-increasing burden. She explained that initially, she had even tried to keep her epilepsy a secret from her husband:

> *"I just think it's* [having a seizure] *undignified. It's such an undignified thing and that, to me, is a big part of it, probably the fear of having a fit. And I think it is so*

undignified if I'm being honest. I remember my husband saying to me when he saw me have the first fit he said, 'I just didn't know what to do'. I'd never told him about my epilepsy or said to him well this is what you do erm…and he said 'I didn't know what to do' and he phoned an ambulance and they sort of said look there's not really anything we can do if she's coming out of it you know this is what you do, you know put her in the recovery position blah, blah, blah. But he said 'it was awful because you never told me'. And I did feel uncomfortable him seeing me because at that stage we were living together and everything and I knew that I loved him and he loved me but I still felt uncomfortable. I don't know, I don't know…I just…there is a real issue of, as I say, vanity and I know that's a terrible thing to say but that is how I feel about it. And probably a lot of people who have epilepsy feel like that. I think it's embarrassing. I think you feel embarrassed, you know. And that's probably for me…I felt uncomfortable coz it's not like just fainting; you know, it's the shaking and everything".

Although Fran's husband was now aware of her epilepsy, secrecy about her condition was still maintained in relation to her three boys. Fran reflected that:

"(…)I will speak to them [her boys] *because I just think it would be such a frightening thing to happen for them to see. I just think they would be so upset by it and they do need to know and understand. But, I mean, while we were away last week I wasn't well one day, I couldn't, I got up and you know, I had a mycloma* [type of seizure] *and I said to my husband I'm going to have to go back to bed and he took the boys down to the pool. And then I thought what would have happened if I'd had a fit down by the pool, you know. And I was just so upset the whole day because I thought what would have happened in front of everybody and the boys. And then my holiday was ruined because I was thinking what would have happened if they'd* [her boys] *have seen that* [seizure]*. So they do need to know and I need to, you know, either get some literature for them to read may be or you know, obviously for me to discuss it with them".*

The realms of domestic life also appeared to provide the context in which the notion of normality carried the potential to create tension; there were occasions when participants experienced some of the most hurtful stigmatisation from family members. In Chapter Six, for example, Ashley spoke of her husband's rejection of her condition and his reluctance to give emotional support to her. Returning to Fran, she felt that her mother and father were ashamed of having someone with epilepsy as a member of the family. Fran recounted the words spoken by her mother shortly after she had married, "(…)*you were lucky to get someone to take you on".* Fran believed her mother would not have held such an opinion had Fran suffered from another, in her own words, *"less embarrassing"* condition:

"I've noticed as well even with family they'll say 'Oh no, we haven't told them', you know, and I think it's as if they are a bit embarrassed about it [Fran having epilepsy] *but I do think that it is a little bit, you know, maybe it's back to that old thing that people thought you were a bit mad if you had epilepsy you know a long time ago. I don't know what it is but I do find that with my Dad he's sort of 'well we haven't*

told anybody that you have epilepsy'. So you know you do feel that other people are embarrassed about it…whereas, say it was diabetes or something then they probably wouldn't hide it. And I've noticed that none of my husband's family know about it either which I found strange when I found that out. And they're probably doing it thinking of my privacy but you know, I thought well if I had diabetes or something, they probably would have told them. It's, I think there is a strange erm…you know, sort of persona around epilepsy that you know it is something that you don't talk about. That's how I feel about it. And I encourage that probably because I don't talk about it either".

Fran's own and family experiences in relation to concealment reflect the concept of '*disvaluing treatment*' as theorised by Schneider and Conrad (1980, p36). This disvaluing appears also to be mirrored in Fran's views of herself. *'Parental training*' or *'coaching'* in the stigma of epilepsy thus becomes a self-perpetuating philosophy in that the more significant others convey epilepsy as something bad or to be hidden, the more likely the person with epilepsy perceives it as something to be concealed (Schneider & Conrad, 1980 p36).

It is arguable that failure to keep one's epilepsy a secret could in fact worsen the assault on sense of self. The consequences of discovery and of one's own failure to maintain a preferred identity could compromise one's own credibility. There is also the risk that an act of secrecy, when compromised, may increase discreditability, as the concealing behaviour could be interpreted as cheating or dishonesty.

Charles provides an example of one such scenario. Following his first seizure Charles was previously diagnosed with nocturnal epilepsy and, as a consequence, medically discharged from the Royal Navy. He believed his condition would not impact on his ability to perform in his new day job in Civvy Street and therefore did not disclose his epilepsy to his new employer:

"It's very hard to find employment, you don't know whether to tell them you've got epilepsy because employers hold it against you. They [employers] *say to you* put *it* [epilepsy] *down because they can't discriminate but I mean I lost me job because they found out I had epilepsy. I never put down that I had epilepsy. I researched this quite thoroughly when I lost me job. Now according to the Union and what I got on the internet I didn't have to put that on my application form or tell them I had epilepsy until I'd got the job. Now they disputed this quite strongly, they said that I did and that I should have told them, so when they found out they dismissed me for not telling them. I was trying to fight it with the union, and that was going on for nearly six, seven months and they said I got to take them to a discrimination tribunal. Me union rep said that it wouldn't be worth the hassle, so then the next thing I got a letter with a cheque in it. I asked the union rep should I accept it or,*

and he said, 'yeah, you might as well'. He said I might as well 'take it on the chin' as they weren't going to give in. And that was it really".

Charles' anticipated fear of encountering enacted stigma, and the dire consequences (legitimate or otherwise) of discovery are evident in the above comment.

7.3.3. Information management

Managing information about oneself was another strategy used by participants to gain acceptance in various situations, thereby diminishing the risk of being stigmatised and potentially making it easier to maintain a desired identity:

> *"There's only my husband that I will talk to about it* [epilepsy]. *There's only him really I speak to about it, there's nobody else, not even friends, I don't speak to people about it. It's a kind of embarrassment".* (Fran).

My participants told stories of two distinct types of information management - strategies of withholding and strategies of approach. Controlling information meant that participants had to decide not only to whom they would disclose but how much and what information they would divulge. However, information management was not just a pre-determined strategy of either withholding or approach but rather a complex, situationally informed, combination of both in that sometimes participants withheld information from certain persons and in certain situations, while in other circumstances or with other people they did (or could) not. As Schneider and Conrad (1980) note, referring to the *'revolving door'* (p37) of the closet of epilepsy, the same person can be both *'open' and 'closed' during the same period in their lives* (p38).

In the current study negotiating the rationale or justification for disclosure was not only related to epilepsy itself but also to the participant's social beliefs and the circumstances in which the social interaction took place. As an example, Brenda spoke of a situation that led her to disclose her condition to a neighbour:

> *"Now it's funny about the 'living with epilepsy'. I mean I've lived here for over four years and since I've been off work, I mean I've always worked, I'm thinking I bet they* [neighbours] *think I'm not working anymore. Jan* [a neighbour] *who lives across from me, she came over one time, talking about some kids playing out and making a bit of bother for her little lad and err… she'd heard that Peter* [Brenda's son] *was being picked on out there and err I said 'yeah' and said 'his dad* [father of boy causing trouble] *came over half past eight one morning ranting and raving at me' err… and I said 'I think he were expecting me to back down but I didn't you know, I stuck up for meself and for Peter. It doesn't bother me I can look after meself, but I'd mentioned to her* [neighbour]*, that I'd been off now for a while, and I*

> *said 'I have epilepsy'. And I thought I never bloomin told anyone out right like that before and she said 'Oh, right'. That night I'm thinking God I don't want, I don't want anyone to know…but I think because I've not been at work, I'm thinking Oh people are going to think she's skiving and all this, you know, and I'm not skiving, and I've worked all me life – I'm off for a genuine reason."*

The neighbour had called at Brenda's house during the day and, as she explained, *"I was in me night dress; didn't want her to think I was a skiver or out of work on the social*'. Brenda reflected on the upset she felt as a consequence of this disclosure – previously she had only disclosed to family, close friends and employers. It appeared, however, that on this occasion Brenda believed that having the label of epilepsy was <u>more</u> morally and socially acceptable than having the label of 'unemployed'. This is interesting, because it suggests that individual's' may interpret events or happenings within a 'hierarchy of stigma'. The notion of a hierarchy of stigma, was also implicit in Fran's interpretation of a comment made by her mother - "(…)*you were lucky to get someone to take you on"* – in which she believed her mother would not have held such an opinion had she suffered from another, "*less embarrassing"* condition. Returning to Brenda, while her openness about her epilepsy enabled her to legitimise being off work, this scenario demonstrates the dilemma in social relationships faced by people with epilepsy. Should they conceal their condition or make it evident; with efforts to negotiate one's identity potentially resulting in either success or failure? In Brenda's case we know from her work-related stories, articulated in chapter six, the importance she placed on her ability to work. Thus, disclosing her epilepsy not only appeared to reflect perceptions of her own work ethic but also served to establish her credibility as 'worker'. On the other hand, making epilepsy visible could result in felt stigma. Brenda continued:

> *"I mean, she* [Jan, neighbour] *wasn't bothered* [about Brenda's disclosure of epilepsy] *so I can't say I felt like I had a label put on me, it was probably the complete opposite, do ya know what I mean? Because, I didn't want to be different than anyone else. But I knew that I were. And I were none the worse thought of, but it was just me".*

An alternative way some participants managed social situations was to actively disclose information about both their own condition specifically and epilepsy in general to acquaint others about the condition. Schneider and Conrad (1980) refer to this strategy as *'instrumental telling' (p39),* and propose its purpose as being to assist an individuals' attempt to mitigate the potentially negative impact of their epilepsy on one's self and in daily life. Alan demonstrated this point by explaining that now his girlfriend was *"sleeping*

over" he had wanted to prepare her for what to "*expect"* and what to "*do"* in the event of him having a seizure:

> *"I know what she'll be like, she'd get worried, she'd start crying probably and start being scared and everything, but I don't want, I don't want her to do that. I just want her, if she wakes up and I'm having one, I've said to her, 'just ignore me, turn over and go back to sleep'. I just want her to go back to sleep. Just leave me alone and not make a big fuss of me and go back to sleep. Because that's what I don't like; people, they make a big fuss of me".*

June and Ricky also actively disclosed their epilepsy:

> *"If I've met anybody, I've told them. I've said, I'll tell you now 'I'm epileptic just ignore me*'. *I'm not looking for sympathy, I'm just telling you that, erm…if I take one* [a seizure] *just ignore me".* (June).

> *"Well yer have to tell, tell yer family like cause there's something wrong with yer, especially like they'd want to know why you weren't working so, as I say, they all know what to look out for and I told them all how it affects me, what I was doing, where I had to go to the hossy and all that. All the things I could and couldn't do and as I say, they all know what to look out for".* (Ricky).

Likewise, Jessica spoke of how she always carried leaflets about epilepsy which she handed to work colleagues and friends, and how she had spoken about epilepsy at health and safety sessions conducted at her place of work as a means to providing information about the condition to work colleagues.

Such strategies were used as a means to increase the knowledge of others and to mitigate the fear others might experience on seeing an individual have a seizure. Jessica noted that the majority of people would be dealing with the *"unknown"* when they were confronted with someone having a seizure and that it was important for them to have knowledge about what to expect as well as information about what to do:

> *"I mean, if I'm honest, even though I have it* [epilepsy] *myself, I don't know what my reaction would be if I saw someone have an epileptic fit. I suppose you don't know until you are in that situation, but I guess it's that people are dealing with like the unknown and they don't know what to expect. I always say to me mates if you see me having an epileptic fit, don't be surprised if I did wet myself, don't be surprised if I was foaming at the mouth and it'll last about a couple of minutes. I said if it goes on for more than about five minutes or something, then you need to get an ambulance, other than that just let it happen, put me in the recovery position and let me sleep somewhere safe".*

The above strategy of anticipatory *'preventative telling' (*Schneider & Conrad, 1980, p40) - another form of instrumental telling - served to influence others' actions and / or ideas

towards the individual with epilepsy and toward those with epilepsy as a group. It occurred when participants believed it likely that others, especially those with whom they shared some routine, would witness their seizures (as another example, Brenda used 'preventative telling' to inform prospective employers about her condition). Jessica's comment above demonstrates her assumption that others would not be frightened if they too learnt that epilepsy is a medical problem. By others knowing what 'it' is, Schneider and Conrad (1980) argue that a medical construction of epilepsy and seizures comes to the fore. Constructing epilepsy as a medical problem provides a means by which to influence others' reactions should a seizure occur, thereby removing blame and responsibility from the person with epilepsy for their abnormal behaviour.

7.4. Seeing oneself as different in relation to other people with epilepsy

A number of my participants expressed mixed feelings about fellow suffers of epilepsy, who they considered to have characteristics they did not readily wish to associate with themselves. Implicit in such sentiments was the sense of seeing oneself as different from others with epilepsy, while simultaneously sharing an 'outsiders' or wider society's views and attitudes about that differentness. Stuart, for example remarked:

> *"It felt like a stigma, because people used to look at yer as though you had leprosy or something, cause I think epilepsy was always seen like. I have seen attacks, like this lad here, you know, with the helmet on; I've got a young neighbour he lives just over there. A young kid, he's only about 14 and mine's mild compared to him. I've seen attacks where people have bit their tongue and passed water and everything, go on the floor. I never had attacks like that. I never bit me tongue and have never passed water, you know weed meself. And, err…so I was lucky in that respect. People seeing that they always typify, typify an epileptic attack as that, people on the floor. You know squirming around, were it's not that, it's quite a few ways, loads of forms of epilepsy".*

> *"I always remember the first attack I ever seen somebody have was in a main road where I used to live and he was on the floor kicking, and foaming at the mouth which used to make them look bad, it was bad anyway, but it made the epilepsy look more. It distanced people, you know frightened a bit. Whereas now the attacks are anything from petite mal to grand mal and it's all epilepsy".*

Brenda too reflected:

> *"I remember going* [to the outpatient epilepsy clinic] *and I was sat amongst all, and it sounds awful this, it sounds awful. I was sat amongst all these other people and one had, you know, the safety helmets that they wear, and I was thinking - I shouldn't be here, I shouldn't be here".*

Observations of, *"I'm not like that", "I don't need to wear a helmet" "I'm not fitting", "I don't wet me self",* were acknowledged by participants in relation to a number of circumstances where others with epilepsy had been observed. Such observations might be considered as notions of self-stigma. Conceptualising stigma as a combination of individual and social phenomena, the importance of addressing self-imposed, as well as institutional, stigma is brought to the fore (Link and Phelan, 2001b). Self-imposed stigma is the degree to which individuals internalise perceived public stigma (Corrigan & Watson, 2002) and occurs when an individual comes to expect the application of a stereotype to him / herself and out of fear of rejection, acts as if discrimination has already been imposed (Pinel, 1999). In the words of Brenda, *"people don't stigmatise me I stigmatise myself because I know I am different".* The process of self-stigma, as theorised by Link (1987), is described through three processes: stereotype awareness, stereotype agreement, and self-concurrence. Stereotype awareness describes an individual's perception of cultural stereotypes towards stigmatised individuals; stereotype agreement describes the degree to which an individual endorses the legitimacy of public stereotypes and self-concurrence describes the degree to which individuals believe these stereotypes apply to themselves (Corrigan et al., 2006). Self-stigma appears to play a central role in relation to mental health stigma, not least due to the potential ease of concealment of mental health problems when compared to other stigmatising conditions (for example physical disability).

This notion of self-stigma also appears relevant in relation to my own participants, as articulated above. Moving from identifying others as having epilepsy (and therefore being different), to seeing oneself as having epilepsy (and therefore being the same), creates a sense of disruption to one's identity, yet at the same time the clinical and classificatory ambiguity around epilepsy appears to enable participants to distance themselves from the label that connects them. This self-stigma can lead to disengagement coping, such as denial of potential health concerns in relation to epilepsy. To refuse to recognise 'sameness' and to see oneself as unlike 'observed' others is perhaps a way of escaping a sense of risk, both physical and / or emotional. Narratively, this distancing offers the possibility of adopting a new stance in relation to how these participants present themselves to others. Sense of difference in these instances is perceived in relation to others with a similar condition, rather than in relation to a comparison of self to so-called 'normals'.

An alternative interpretation, and one perhaps more easily understood than the notion of self-stigma, is that my participants' expressed observations simply that reflect what is

known clinically – that is, that there are a multiplicity of epilepsy types, as reflected in the recent adoption of the term 'the epilepsies' (NICE, 2012). In either case, from the perception of those who suffer from the condition, it appears that epilepsy does not carry a single identity. The potential for adopting strategies of concealment and distancing offers a means whereby individuals with epilepsy can position their own identify differently from others who carry the same label. This in turn carries implications for developing a politicised epilepsy model that attempts to negate the impact of stigma. While I would argue the importance and relevance of foregrounding the heterogeneity of embodied experience, the fact that participants within this study saw their experiences and epilepsy as different to others, also limits the opportunities for homogenised resistance and challenge. The political consciousness of people with epilepsy becomes effectively neutralised without a shared conceptual framework.

These issues are not easily addressed within the current study. However, I argue that self-stigma carries relevance for people with epilepsy and as such there is a clear need to further investigate this concept; both in relation to its impact on an individuals' identity with epilepsy as well as in relation to the epilepsy community as a unified, politicised group. Identifying the tensions that exist between individual and group conceptualisations of epilepsy identity will contribute to a better understanding of a complex and multifaceted experience and likely assist in identify barriers and facilitators to promote positive change in public perceptions of epilepsy and decrease epilepsy associated stigma.

7.5. Challenging stigma

Understanding and dispelling stigma is one of the aims of the Global Campaign Against Epilepsy - 'Out of the Shadows' - initiatives (De Boer, 2002) – not least because stigma, at a societal level, presents a major public health challenge (WHO, 2006), as well as a personal challenge for people with epilepsy. However, stigma though powerful and enduring, is not inevitable and can be challenged – which creates a mandate for researchers to examine ways to decrease stigma.

In this study participants identified a number of strategies they believed would be effective in demystifying epilepsy, educating members of the public and reducing the stigma associated with the condition. Educating others about epilepsy in order to neutralise stereotypical constructions of the condition was considered an essential pre-requisite for facilitating positive change. Based on their views of how others perceived epilepsy,

participants believed that enhanced public understanding of the condition, through public epilepsy-awareness campaigns would change peoples' beliefs in a positive way. Jessica's expressed views echoed the sentiments of other participants in this study group:

> *"It's a lot about people's pre-conceived ideas, you know, flashing lights on TV, that sort of thing. It's difficult to know how to sort of stop people coming to all these sort of misconceptions? I'm not sure you ever will but it's about education of people isn't it? I think there should be institutional or organisational campaigns as well as public awareness. Even at school, I don't think you even touch on anything like diabetes or asthma or epilepsy or anything like that; certainly never did when I was there, whether it's changed or not, I don't know. You go to school, you go to college, some people to university, you go to your job, and people aren't educated about conditions and they are not going to be educated unless it's got something to do with them or their family or friends or something like that. What is needed is continuous awareness campaigns at different stages of people's lives. Erm…you know, like you have big cancer campaigns and adverts about smoking etc. but epilepsy, there's nothing? I think it's something like half a million people in Britain have it* [epilepsy] *but as a person with epilepsy you feel a minority. You don't tend to hear anything in the newspapers or media or anything like that. I never even knew Epilepsy Action existed! Erm…like I say, me Mum found out about that. It* [epilepsy] *lacks profile; it's not got awareness as much as other conditions. And I think that's why people are so, as I say, judgemental. But people are like in generations, in the sense that my granddad probably got a completely different outlook on it, view of it than I have. But I think you don't really know what people's reactions are until you broach the subject, like I say people's views are stereotypical".*

Stigma is by no means an automatic consequence of possessing a discreditable attribute (Schneider & Conrad, 1980). As such, the significance of having epilepsy is also informed by the perspective of individuals with the condition. Thus a discreditable attribute only becomes relevant when perceived as discreditable by the affected individual, whether or not those perceptions are actually applied by others. Interestingly, none of my participants articulated that they themselves had a part to play in the construction of epilepsy as a stigmatised status or articulated the need to challenge their own perceptions of stigma. This highlights the importance of raising awareness of intra-personal resources within stigma reduction interventions (see Figure 8). Here, for example, access to counselling, cognitive behavioural therapy and self-help group services will likely reduce the psychological struggle faced by many people with epilepsy. Help to support individuals with epilepsy and its psychosocial impact on a personal level is required in tandem with raising public awareness and promoting positive attitudes about epilepsy and its stigma potential.

In this regard, Muhlbauer (2002) argues that stigma can only be addressed when stigma reduction interventions target each of three identified levels of stigma in tandem with each other. Muhlbauer defines these three levels operate as: the internalised (the actions and reactions of the person experiencing the stigmatisation), the interpersonal (the actions and reactions of significant others) and the institutional (the societal position taken as reflected in its laws and statutes). Similarly, a literature review conducted by Heijnders & Van Der Meijs (2006), to identify stigma-reduction strategies and interventions in the field of HIV/AIDS, mental ill health, leprosy, tuberculosis and epilepsy identified five levels at which interventions and strategies are being implemented to challenge stigmatisation (see Figure 8). These levels were identified at the intrapersonal, interpersonal, community, institutional, and governmental / structural level. The effective strategies identified mainly concentrated on the individual and the community level. In order to reduce health-related stigma and discrimination significantly, single-level and single-target group approaches are not enough.

As noted in Chapter Three, epilepsy has long suffered the application of formal sanctions including for example, anti-marriage laws, legitimised sterilisation, and institutionalisation and immigration prevention. Despite the fact that in many countries those suffering with epilepsy are deemed to have a 'prescribed disability', and as such, an entitlement to protection under the law, not all restrictions are supported by a clear evidence base. People with the condition are still the subject of discrimination, especially in relation to driving and employment. Although some restrictions have a rational basis (for example, diagnosis of uncontrolled epilepsy and driving regulations), others appear less rational, for example, people with a 10 year seizure free history are still denied permission to co-pilot a plane. Lee (2010) reviewed the legal framework for epilepsy within the United Kingdom since the introduction of disability discrimination legislation and found evidence of their effectiveness in relation to stigma prevention to be scant. Fernandes and colleagues (2011) argue that the issue around such legislation is that potentially it serves to push discrimination *"underground"* (p57) as it is impossible to legislate for attitudes that inform enacted stigma. Similarly it may prove difficult to contest discrimination (as in the circumstances described above by Charles) when an employer needs only to state that a person was not suitable for a particular job. The researchers further argue that such legislation may even have the opposite result to the one intended, by reinforcing stigma concepts. What is required therefore is a patient-centred approach (Heijnders & Van Der Meijs, 2006), which starts with interventions targeting the intrapersonal level, to empower

affected persons to assist in the development and implementation of stigma-reduction programmes at other levels.

Figure 8: Stigma reduction strategies

LEVEL	STRATEGY
Intrapersonal	• Counselling • Cognitive Behavioural Therapy • Self-help Support Groups • Treatment • Empowerment
Interpersonal	• Care and Support • Homecare Teams • Community-based Rehabilitation
Community	• Education (social marketing; mass media) • Contact with others living with the same condition
Institutional	• Training Programmes • Policy Development
Governmental / Structural	• Legal Interventions • Rights-based Approaches
Adapted from: Heijnders & Van Der Meij (2006)	

7.6. Conclusion

The physical manifestations of epilepsy are transient, yet the psychosocial impacts can be long-lasting (Snape et al., 2015). Stigma generally causes great suffering (Jones et al., 1984) including, for example, anxiety, shame and loss of sense of self (Fernandes et al., 2011; Jacoby, 2014). My participants' accounts, for the most part, described episodes of felt rather than enacted stigma and highlighted their sense of personal responsibility in seeking to alleviate the fear of felt stigma and the potential for enacted stigma. While participants recognised the social component of the difficulties they experienced with stigma, the strategies they adopted to legitimise their social standing were personalised and encompassed tactics of avoidance and control, rather than challenge – with the exception, on occasion, of Jessica. A key message from this data is that nothing much appears to have

changed since the work of Schneider and Conrad (1980; 1981; 1988), Scambler and Hopkins (1986) and Scambler (1989), in so much as epilepsy is still seen as predominantly a 'personal' rather than a 'political' issue. This sets epilepsy apart from many other disabilities, which have become highly politicised. As an example, in South Africa (Pearce, 2009), HIV / AIDS-related stigmatisation and discrimination became the very experiences that created the potential for successful collective, social action to take place to challenge institutions, to gain access to HIV testing and treatment facilities and to overcome severe stigmatisation. In South Africa, HIV positive people have, according to Robins (2006, p314), turned stigma into a *"badge of pride".* Making claims on the basis of their HIV positive status has enabled the creation of a political space for the articulation of their struggle and the mobilisation of resources to promote local, national, and global positive change; what Appadurai (2000; 2002) refers to as 'grassroots globalisation'.

Within the current study, the cost to participants associated with the use of personalised strategies of distancing, concealment and information management was failure, by the majority, to affiliate themselves with people with epilepsy in similar situations. None of my participants allied themselves, either emotionally or politically with organisations, for example Epilepsy Action, where an identity as a person with epilepsy could potentially be framed more positively. In addition, while concealing or withholding information about oneself enabled participants to gain acceptance in certain situations, and thus diminished the risk of stigmatisation, it also led to alienation from others through diminished social circles and the potential for stigma coaching.

Health professionals who care for people with epilepsy need to be mindful of the problems concerning stigmatisation as this could make for more sensitive relationships between patients and health care providers. An increased understanding of epilepsy stigma and its potential consequences for the identity of those with this condition can subsequently lead to an understanding of the problems that exist among individuals attempting to come to terms with their condition. Participants' accounts demonstrate that stigma is not a fixed concept in the lives of those with epilepsy; rather it is played out as a dynamic process which is both determined by and responsive to contingencies of everyday life and contextual circumstance.

A review of the literature around stigma in the lives of adolescents with epilepsy (MacLeod & Austin, 2003) highlighted that qualitative rather than quantitative research approaches

may be better able to uncover the subtleties and complexities of how people with epilepsy experience stigma and how it affects their lives. The conceptualisation of stigma as a dynamic process, informed by analysis of patient stories, I would argue has the potential to assist health professionals to recognise and appropriately position anti-stigma interventions to minimise stigma perceptions. Such narratives could provide information about alternative and previously unrecognised mechanisms by which stigma works.

CHAPTER EIGHT

8. Reflections, summary of findings, implications and conclusion

8.1. Introduction

Approximately 1 in 103 people in the United Kingdom (UK) have epilepsy (JEC, 2011), equating to 600,000 patents in the UK today (ONS, 2011); an equivalence of approximately 87 newly diagnosed cases each day of the year. Epilepsy is not only the most serious and the most common neurological condition seen in primary care (Lambert & Bird, 2001), but is also embedded in multiple medical, social, and cultural discourses (Tempkin, 1971). Thus, phenomenologically, this work has come from the standpoint, not of epilepsy categorisation, but of sensation – *how is epilepsy experienced*?

I would argue that epilepsy becomes objectified within medical discourse when these sensations become translated into symptoms. I have therefore endeavoured within this study to take up the postmodern challenge and to look critically at any opinion that presents itself as certainty or an absolute truth. In this regard, the medical discourse that defines epilepsy as, for example, neurological, symptomatic or idiopathic, and as recurrent unprovoked seizures, speaks to one aspect; the physiology of this condition. However, this does not encompass the psychosocial dimensions of the lived experience. Successful treatment of epilepsy needs to extend beyond symptom and seizure control if those with the condition are to be enabled to participate in, and be accepted by, society (Vaccarella, 2011). To contribute to this endeavour, in the previous chapters I have explored how the adults with epilepsy in this study experienced, interpreted and managed their condition.

In this concluding chapter, I review the original research question(s) and elaborate on the psychosocial effects of epilepsy, the effects the condition has on identity(s), and the resources individuals tap into in order to cope and reconstruct their biographies and accomplish legitimisation (Bury, 1982). I reflect on the value of a narrative research approach. While I do not propose these epilepsy narratives put forward an alternative 'absolute truth', or assert that they expose an alternative theory of epilepsy, I do however argue that they stand on their own as constructions of truth for the individual. The

postmodern perspective I have taken sensitises us to hear all perspectives, each of which must be considered for their contribution to a fuller understanding of epilepsy, for their wider implications for the health and social care of people with epilepsy, and for informing the pursuance of future research needs in this field.

8.2. Reflecting on a narrative approach

8.2.1. How has the methodology influenced the research process and outcome and what are its limitations?

Given the call for narrative medicine in epilepsy to aid the social and personal adjustment of patients to this disorder (Alcauskas & Charon, 2008; Vaccarella, 2011), I sought to foreground my participants' personal perceptions of their experiences as a means to developing a person-centred understanding of what living a life with epilepsy means.

This study represents one account of experiences of living with epilepsy and adds to the ongoing discussion on health and narrativity. The use of the narrative approach in eliciting the epilepsy experience determined the nature of data collection, analysis and the subsequent interpretation of my findings. My request to patients for their participation (see Appendix 5 and 6) was framed around findings from previous – largely quantitative - research about the impact of epilepsy on quality of life; primarily, that epilepsy is not just a medical condition but also a social label. We do not have a clear idea about how these findings reflect the individual epilepsy experience. I was therefore interested in how a person might deal with this label and the stigma that is sometimes associated with having epilepsy and the potential impact this might have on his or her wellbeing.

I accept that by framing the discussions in this way I may have influenced the content of my participants' accounts. However, this framework also afforded the opportunity to assess theories of stigma and biographical disruption for their relevance and applicability to a sample of adults with chronic epilepsy. In particular, I was interested in ways of thinking, feeling and doing which I hoped would be revealed by the individual's biographical account of their life in certain contexts and at certain times (Wengraf 2001) - I use participant quotes, to enhance the transparency and persuasiveness of my interpretation (Riessman, 2003). The research question(s) was exploratory and aimed to better understand the experience(s) of those diagnosed with epilepsy, as well as to consider how people with epilepsy constructed and articulated their narratives to others and how the narratives were

influenced by others. This required I use small-scale, in-depth, exploratory interviews; using open-questions and following the participants' experiential paths carried the benefit of capturing their own long descriptive accounts, as opposed to being researcher-led. While recognising such narratives are inevitably co-constructed between teller and listener and performed with context in mind (Riessman, 2008; Wells, 2011), this approach nonetheless revealed diverse experiences, embedded in participants' own expectations and concerns.

However, a noteworthy impact on the process and means of data acquisition is that my participants were recruited from a single, specialised, regional epilepsy centre and self-selected into the study. The nature of this sample may be unique as these participants were well-linked to tertiary care services and so to a particular healthcare experience. In addition, it may be that those adults with epilepsy with a 'story to tell' and the ability to communicate that story and related concerns effectively are more likely to volunteer. The method of recruitment also meant that there was no ethnic diversity. Previous research suggests that a more diverse ethnic representation would have been valuable in developing understanding of the meanings and management of epilepsy across cultures (Small, et al, 2005). The size of the research sample may also be considered a limitation – I interviewed only fourteen adults with epilepsy for this study. Although the interviews yielded rich descriptions, a larger number of interviews might have yielded greater variation in the details of the 'life with epilepsy' stories. As such, these stories may not reflect the generality of experiences.

My account of these experiences is presented in Chapters Four through Seven. I have made every attempt to promote my participants' authenticity as individuals who are experts in the field of their own experience. However, along with their 'voices', I have also imprinted upon the data both theoretical considerations and my own personal perspectives in order to provide structure to the presentation of findings. To bring my participants' voices, through my writing, to the reader has presented a personal challenge; not least because as Ricouer (2005) asserts, textual accounts of narrative invite a *"hermeneutics of suspicion"*, wherein personal reports run the risk of losing their validity. In line with my epistemological position, I recognise that any subsequent readings of this text are open to numerous and varied interpretations - for there is "*more than one way to interpret a text*" (Ricoeur, 1976, p76) and "*different but equally valid interpretations are possible*" (Stern, et al 1999, p355). Hence, the reader may apply interpretions to the findings that are different

to those I have articulated; highlighting the significance of context (Riessman, 1993) upon both meaning and interpretation. In evaluating my research findings for trustworthiness, credibility, and authenticity (Bailey 1996), my own position is that a study of this nature is credible when it presents faithful descriptions and can show how interpretations have been arrived at. That said, I have endeavoured to provide a transparent account of the research process which I hope will promote confidence in the trustworthiness and authenticity of my interpretations.

8.2.2. The role of stories for both patients and practitioners

This study contributes to the sociological literature regarding the experiences of adults living with epilepsy (Schneider & Conrad, 1983; Scambler, 1989; Good & Good, 1994; Kleinman et al, 1995; Faircloth, 1998; 1999; Jacoby, 2004). By examining how people with epilepsy cope and respond to their condition, this research also contributes to the chronic illness literature exploring disruptive life experience and an individuals' response to such disruption (Bury, 1982; 1988; Williams, 1984; Corbin & Strauss, 1987a). Charmaz (1983) speaks of the losses associated with chronic illness, including for example, diminished sense of self, and the strain it places on relationships. In this study I too have demonstrated how epilepsy created problems with identity and relationships.

The benefit of a narrative approach is that it does not enforce researcher-constructed classifications to explain illness experience or its meaning. In the words of Clandinin and Connelly (2000) *"Narrative inquiry is the study of experience…"* (p189). It is in this vein that I attempted to give voice to those affected by epilepsy. The results of this study underscore the importance of people's lived experience of health and illness, by providing insight into the multifaceted nature of this experience and illuminating the everyday medical and social contexts within which epilepsy is lived – thus facilitating greater social understanding. Knowledge of the negative impact(s) of managing a chronic illness is important because it promotes understanding of the psychosocial consequences of illness; however by also highlighting the positive elements of participants' adaption to epilepsy, I have been able to bring to the fore a more complete view of the complex impact epilepsy can have on individuals' lives.

The issue of temporality is relevant here as my participants' narratives covered a historical period that ranged from 3-58 years. Often participants reflected on events and symptoms

which they now attributed to their condition, but which had occurred prior to them receiving a medical diagnosis of epilepsy. Mattingly (2000) makes the distinction between narrative time and time inherent in everyday life, with the former being grounded in human experience. This means that individuals are story tellers connected to social practices that shape the creation of memorable experience.

Stories told within the context of the current study described both retrospective and contemporaneous events which contributed to accounts of a life lived with epilepsy. I was therefore provided with the opportunity to analyse longitudinally the changes that occurred in my participants' lived experiences, while remaining mindful that the stories were told from that individual's present perspective. The extent to which my participants' status at the time of telling informed their recollections of the past is somewhat difficult to ascertain. However, the strength of participants' stories, retold in the present, lies in their melding of past and present. By recognising this integral function of storytelling, stories offer health professionals insight and can guide clinical practice by identifying needs and where existing services fall short of meeting those needs (Kleinman, 1988; Greenhalgh, 1998; 2003). Indeed, stories have a great deal to tell us about living with illness; individuals need others to listen to their stories and to provide them with appropriate recognition. As Frank (1995) argues, we all carry the responsibility to be witnesses. Narratives, as sources of knowledge, have much to teach us about coping with chronic illness, suffering and experiences of care.

Health professionals would be well advised to consider their own understanding of truth as a pre-requisite for understanding human behaviour and for augmenting the validity, acceptability and genuineness of care-giving. In the context of the current study, I argue that health professionals can listen to how individuals talk about their bodies and their experiences in relation to those bodies, in order to better appreciate the challenges faced by those living with epilepsy, their families and their friends. Often, forces outwith the healthcare professional arena determine the direction and delivery of health care. However, when limited financial resources drive policy and service development rather than the genuine needs of patients, I suggest an opportunity presents itself for health professionals to emulate the narrative paradigm. As articulated by previous authors (Greenhalgh & Hurwitz, 1999; Docherty, 2000; Charon, 2001; Alcauskas & Charon, 2008), the very nature of this approach honours the narrator, providing health professionals with

the opportunity to live out this core value by listening to, hearing and giving voice to a group of individuals who have much to say that should be heard.

I argue therefore, that epilepsy narratives, with their multiple and competing accounts do much to enrich understanding and increase options for action (Gergen & Gergan, 2011). Hidden stories can be surfaced and the patient's voice is legitimised. Stories have the power to complement current approaches to epilepsy care as health professionals are able to become sensitive to the challenges, impacts and meanings of epilepsy faced by those with the condition, and, as a consequence, impact positively on traditional medical practice. Kleinman (1988) asserts, *"It is clinically useful to learn how to interpret the patient's and family's perspective on illness. Indeed, the interpretation of narratives of illness experience, I would argue, is a core task in the work of doctoring…"* (pp xi-xii).

Such "*empathetic listening*" (Kleinman, 1988, p54) requires medical professionals perhaps to adopt a different stance to that of traditional medical training and to set aside possible notions of power, based on their acquired expertise and / or their perceived social positioning. It invites members of the health profession to learn from patients before seeking to act upon them. Understandably, this shift in positioning and thinking may prove difficult to embrace for many medical professionals whose disposition and dedication is grounded in a system of power imbalance (Docherty, 2000).

8.3. Summary of findings

8.3.1. A framework for understanding the journey of epilepsy

In Chapter Five I sought to search for commonalities in the 'life with epilepsy' stories told by my participants. The challenge was to venerate the particularities of the fourteen storytellers in this study and to honour the individuality of each, while at the same time identifying common experience. The common themes identified in this study were represented by the four components of the epilepsy plot line; namely:

- *The process of discovery*
- *Searching for a cause*
- *Negotiating uncertainty and risk*
- *Striving for control*

Can the commonalities identified in this study be generalised to other adults living with epilepsy? It must be said that the heterogeneity of the fourteen voices does not guarantee this. For the illness story is as unique as the person who narrates it and in attempting to draw conclusions I might reasonably be accused of running the risk of missing the essence of the individual story.

That said, the common themes identified above are enlightening in that they provide a framework for understanding the journey of epilepsy. For the majority of participants, the epilepsy narratives did not include dramatic identity changes at discovery. Labelling did not start at discovery. Rather diagnosis provided the first opportunity for the attribution of a label to that person's identity, with subsequent identity changes only emerging relationally as participants attempted to respond to contingencies of everyday life.

My participants' needs to identify a clear cause-effect relationship as a means to explaining their diagnosis confirms the argument that patients need an explanation of their illness that fits within their own world view in order to create continuity in their lives (Brody, 1987; Hyden, 1995). Participants' stories also revealed that often such an explanation did not exist and they therefore attempted to understand why they had been diagnosed with epilepsy by considering their social behaviour, their own health and their family health histories as possible causes. Often participants were unable to create a positive meaning for the illness because of inconsistencies between medical and familial explanations and their own pre-diagnostic experiences. As a consequence the epilepsy diagnosis did not allow them to make sense of events.

In attempting to resolve the differences between their diagnosis and normalising ideologies of family, social and working life, participants told stories of despondency and distress, the confining and limiting aspects of their epilepsy and the need to take back control. However, these stories did portray how participants attempted to demonstrate control over their epilepsy, even where it was not always fully possible. Most participants described themselves as seeking out information. However, while information was perceived as a valued resource both to inform understanding of epilepsy and related healthcare decisions participants, in pursuit of answers, often found they had to come to terms with the limitations of medical knowledge and conflicting advice from health professionals. This dissatisfaction with information provision was particularly demonstrated in stories that

spoke of medical uncertainty related to the causes of epilepsy and conflicting information in relation to the appropriateness of anti-epileptic drug regimes and information in relation to pregnancy and family planning. Thus, some participants felt that the particulars of their circumstances were not always considered in medical consultations and treatment regimes. No doubt if I had examined the perspectives of medical professionals by affording them the opportunity to tell their stories they might have viewed my participants' stories and their consequences differently. Nevertheless, the perception of some of my participants that medical professionals failed to engage effectively and affectively represents a betrayal of the patient as a situated person, with important implications for the medical management of epilepsy.

The epilepsy plot line provides a narrative model to aid holistic thinking. Consideration of such a model offers current epileptology a practice framework for appreciating the interdiscursive position of epilepsy as a medical, social and symbolic phenomenon. Hearing and discussing narratives about epilepsy may afford health professionals not only the opportunity for understanding but also a means of facilitating patients' agency in the management of their own condition (Vaccarella, 2011). Of equal importance, the framework also opens up the potential for health professionals to identify factors which lead to an individual remaining 'stuck' in a problematic illness narrative (as was demonstrated by Jessica's and Ricky's accounts in Chapter Six and insight to offer assistance and appropriate interventions to that individual in order to promote positive lifestyle change.

8.3.2. Disruption and repair

In Chapter Six I attempted to illuminate how my participants' bodies and selves were affected by disruption and the process of repair. Despite the fact that epilepsy often posed a threat to participants' sense of self and had an enduring impact on their future goals and aspirations, some participants revealed that other disruptive events were, on reflection, more consequential than epilepsy. The social situations of participants – for example, involvement in abusive relationships, divorce, financial hardships and providing emotional and instrumental care for other family members who were ill - exposed them to experiences deemed far more disruptive than epilepsy. The ways in which participants evaluated disruption caused by epilepsy and the factors that influenced individuals' assessments have important implications.

These findings underpin the importance of social and cultural context on consideration of illness. As noted above, previous negative life events may lessen the impact of epilepsy. Conversely, for those who recounted more positive past experiences, as an example, a valued career, having epilepsy was perceived as more problematic. Age and gender may also explain the differences in 'life with epilepsy' stories because the narratives did reflect age- and gender-specific aspects of identity and difference in relation to normalising ideologies. This was reflected in accounts around stereotypical perceptions of being a teenager, the need to be seen as a competent worker; and, the fear of being a bad mother. These factors influenced illness behaviour both positively and negatively. This finding is consistent with the work of Faircloth (1998) who noted that the experience of epilepsy has more than one meaning. Within the current study epilepsy offered unique experiences in relation to particular life contingencies and sets of changing meanings from individual to individual. Reconciliation of disruption was not consistent or sustaining throughout the course of the condition. In addition, while reconciliation may have occurred in relation to one aspect of an individuals' life, epilepsy appeared to remain salient in another or other aspect(s) of the same individual's life. This finding provides an indication that, for participants in this study, positive transformation of identity was partial rather than total.

The multiple form of the epilepsy narrative also reflected the contextual and relational aspects of having epilepsy, as experienced by my participants. Significant here, is that the previous models and typologies offered by Frank (1995) and Bury (2001) only partially reflected the epilepsy narratives I heard. Thus, Frank's restoration, quest and chaos narrative forms did not entirely describe what my participants told me. The repaired physical state, described as the necessary end point of the restoration narrative was lacking in the epilepsy narratives. The restoration narrative requires a complete recovery and while William felt his epilepsy was no longer a problem and the stories of Alan, Ashley and Karen spoke of a positive post-surgical clinical change in relation to their epilepsy symptomology, all four of these participants remained on anti-epileptic drug medication. An end point of complete recovery required by the restoration narrative was an unachievable outcome for my participants with epilepsy. Rather they continued to live with the label of epilepsy and the propensity for seizures; undergoing regular hospital visits for tests and consultations in order to monitor and manage their condition.

Neither do the epilepsy narratives conform to the quest story. Here, Frank argues that the illness is perceived by the narrator as a journey to a different world, where the illness becomes a conduit for enhanced knowledge of self. Among my participants only Brenda and Jessica spoke of their epilepsy as an opportunity to learn about themselves and their relationship to those around them. Others; Yolande, Larry and Martin, spoke of epilepsy as merely another facet of daily life. In addition, the story line of 'being stuck' offered by Fran and Ricky reflected the apparent inability of these participants to move on with their lives. As a result they lacked the extra knowledge that would allow them to view the world differently.

Frank's third typology of chaos narrative, where the disorientating effects of illness leave the narrator with no means to make sense of their condition through a linear account with a clear plot, also failed to account for the experiences of participants with epilepsy in this study. While discrete stories across the sample did resonate with Frank's interpretation of chaos (as an example, the medication and drug side-effects stories articulated by Jessica), this type of story was subsumed within a larger epilepsy plot line. Here, participants told linear stories marked by discovery, searching for a cause, negotiating uncertainty and risk, and striving for (but not always actualising) control (see Chapter Five).

The three types of illness narratives offered by Bury (2001) – contingent, moral and core – were perhaps more easily discernable within the epilepsy narratives. These narrative typologies however, were only definable in relation to discrete stories told by individuals, rather than being representative of an overarching presentation of epilepsy narrative type. The typologies are distinct, however, and in the current study were employed alongside each other, emerging in relation to purpose and context. As an example, contingent narratives comprised those aspects of my participants' story surrounding beliefs and knowledge about the factors that influence the onset and course of their epilepsy, and effects on the body, self and others. Contingent narratives - as demonstrated throughout the stories told within each of the four components of the epilepsy plot line (see Chapter Five) - outline the steps taken to deal with epilepsy and the strategies employed to manage its effects.

Moral narratives are evaluative ones in which individuals seek to account for and justify themselves in the altered relations of body, self and society brought about by their illness.

In the current study, in dealing with biographical reconstruction, participants often presented themselves as culturally competent in relation to working, family and social roles (as demonstrated in some of the stories in Chapter Six and Seven). Bury highlights that moral narratives may include social apologia in which the person attempts to narrow the gap between their previous self-image and what they perceive or encounter as failures in self-presentation or role performance. This was evident in a number of stories recounted by my participants, for example, Brenda, June and Fran.

The third of Bury's narrative forms - core narrative - was not a consistently presented narrative form either across all the epilepsy narratives or within a single narrative account. Core narratives can be considered as the presentation of one's identity through *'genres of expression'* in which the narrator *'emplots'* themselves in a more or less dramatic fashion (Bury, 2001, p278-279). This narrative form enables the teller to account for events and to give shape to them in terms of the way in which they relate to self and others. So, for example, in the current study, I was able to align some discrete stories to a core narrative theme of progression (Robinson, 1990). However, this theme was not consistent throughout that individual's overall narrative; other stories they told were representative of an alternative core narrative, that of regression (Robinson. 1990). Progressive stories portray a positive and more engaged response by the individual and a move towards personally valued goals, while stories which portray regressive qualities highlight a continual discrepancy between valued personal goals and the possibility of their attainment. In their extreme form, Robinson notes, regressive narratives portray tragic accounts, as might be interpreted in the accounts of Fran and Ricky.

However, as an underlying plot my participants' stories do attempt to cope with medical, psychological and alternative explanations of the causes of their epilepsy. While the context and content of all these stories differs, they all attempt to cope with the disruption they report having met with. The similarity of the stories lies in their narrative function, for they serve to demonstrate participants' internally driven, moral obligation to improve their epilepsy both for their own sake and for the wellbeing of others. As arguments, their stories attempt to convince us about the credibility of lived experience, to improve understanding about epilepsy and its psychosocial consequences.

These findings highlight the importance of psychosocial care for those suffering from epilepsy and of close attention to their stories of non-epilepsy related experiences. I would argue that health professionals treating those with epilepsy cannot adequately attend to their health and social care needs without attention to the diverse social milieus they inhabit and their individual needs. While the dominant plot line across participants' stories identifies that there are indeed commonalities across the experiences recounted by people with epilepsy, treating them as a homogeneous group will inevitably interfere with optimal care and service provision.

8.3.3. The role of stigma in the lived experience of epilepsy

Despite advances in the treatment of epilepsy, the social and personal adjustment of patients to this disorder remains a challenge across a number of fronts (Vaccarella, 2011; Jacoby et al, 2014). The epilepsy narratives within the current study provide support for earlier theories related to stigma, in as much as they confirm the stigma that a disease label carries with it (Arnston & Drodge, 1987; Sontag, 1990; Whyte, 1991). The descriptors applied to epilepsy by Yolande, *"It's like unclean… the plague…the mange"* and by Jessica, "(…)*like voodoo dolls and Africa…Bloody witches and all sorts!"* reflect the sentiments of many with epilepsy who still find the quality of their lives compromised by the vestiges of cultural taboos and fears about this condition (Fadiman, 1998; Baskind & Birbeck, 2005; Allotey & Reidpath, 2007), which in the past was attributed to demonic possession or divine punishment (Tempkin, 1971).

Diminished social participation was reported by some participants involving withdrawal from social interaction or a diminished ability to leave the house. These circumstances led to a loss of sense of self and personal control over their lives, a finding consistent with earlier studies conducted around epilepsy stigma and loss (Ratsepp et al., 2000; Jacoby et al., 2004; 2014). Participants often recognised the social component of the difficulties they experienced with stigma. The notion of a 'hierarchy of stigma' was evident as negotiating the rationale or justification for disclosure was not only related to epilepsy itself but also to participants' social beliefs and the circumstances in which social interaction took place. However, the strategies they adopted to legitimise their social standing - distancing, concealment and information management - were personalised and encompassed tactics of avoidance and control, rather than challenge. A key message from this data is that epilepsy is still seen as predominantly a 'personal' rather than a 'political' issue. As a

consequence of this positioning the majority of participants failed to affiliate themselves with others with epilepsy or to align themselves with epilepsy organisations, such as, for example, Epilepsy Action. This sets epilepsy apart from many other disabilities which have become highly politicised (as an example, see Pearce, 2009). My participants' 'personal responses' to a 'political issue' raise a number of questions in relation to what can be done about this? For example:

- What stops a person with epilepsy from seeing it as a political issue that needs resolving at the political / campaigning level?

- Why are the epilepsy organisations failing to get people with epilepsy to see it like that?

It seems likely that as long as people with epilepsy continue to internalise the problem (as a psychological struggle) rather than externalise it (as a social meaning struggle) nothing will really change. I would argue that talking about *'The Epilepsies'* (Nice, 2012) has the potential to contribute to the problem of internalisation, rather than diluting it. That there is a multiplicity of epilepsy types and more than one epilepsy body enables individuals with the condition to position their own identify differently to others who carry the same label. This, I argue, dilutes the potential for a political voice and in turn carries implications for developing a politicised epilepsy model that attempts to negate the impact of stigma. Failure of epilepsy charities to join forces and to press forward a 'group' with a common voice has arguably been a strategic failing of the epilepsy charities.

In their recent report, the Epilepsy Society (2013), as part of their 2013/2014 initiatives reported plans to enter into formal negotiations with other epilepsy organisations to establish a future strategy for collaborations and mergers. Attempts need to be made to clarify thinking in this area and to promote open discussion to identify action-for-change strategies. This call to *"identity politics"* would serve to "*combat the prevailing imagery*" and to "*alter both the self-concepts and societal perceptions*" of epilepsy stigma (Anspach, 1979, p766-767).

8.4. Implications

In this section I consider the implications of my findings in relation to future epilepsy research, health practice and service provision.

8.4.1. For future research

Throughout the conduct of this study I often spent time reflecting on a comment made by Alan's father at our first meeting. He felt I was *"conducting the wrong study*". He suggested instead that I should interview *"family members who have to cope with caring for someone with epilepsy".* While I do not agree with the sentiment that the focus of the current study was wrong, I did come to recognise, during my encounters with participants, the validity of his suggestion for a consideration of *"family members"*. The experience of epilepsy is relational, therefore, a potential area of research not explored by this study, but worthy of investigation, would be to consider the use of a narrative approach in eliciting and understanding the perspectives of family members and significant others of those individuals living with epilepsy.

Often the impacts of chronic illnesses are borne by the entire family, with all those involved being affected. It is likely, in attempting to find ways to cope with and manage the situation of a loved one with epilepsy, that those family members and significant others were also faced with biographical work, embracing both the member with epilepsy and themselves. Using a family case history research approach would assist in exploring consequences in relation to family members and significant others. This would enable them to be listened to as experts on the nuances and meaning of epilepsy within their own familial systems. Noteworthy here is the remark from Alan himself, "*when I got diagnosed with epilepsy, it felt like the family got diagnosed with it as well because they had to live with it"*.

In addition, social support groups are adept at helping affected family members cope with and address the negative impact of chronic illness in a loved one. It would also be of interest to study how narrative approaches might assist in understanding processes / strategies involved in this endeavour.

8.4.2. For enhancing epilepsy practice and service provision

The National Service Framework (NSF) for long-term conditions (DOH, 2005) sets out clear requirements for improving the quality, consistency and responsiveness of services and personalised care. In particular, it emphasises the need to *"treat people with long-term neurological conditions with respect and dignity and listen to and act on their views…"* (p13). Research by Greenhalgh and colleagues (1998; 1999; 2003; 2004) has covered the

evaluation and improvement of clinical services at the primary-secondary care interface, with particular focus on the use of narrative methods to illuminate the illness experience. In practice however, the holism embedded in these approaches and in this NSF quality requirement is not reflected within NICE guidelines (2012). Here the emphasis on care appears to be rooted in symptom management where medical discourse constructs and defines presenting problems and consequently frames healthcare interventions; the consideration of psychosocial aspects of care, with particular referral to psychology services, only being suggested if symptom management is not adequate (NICE, 2012, Section 1.11.1).

I contend the development of a narrative model of care and narrative analysis tools within primary, tertiary and specialist centre care settings will assist health professionals to address the particular combination of a person's physical, mental and social wellbeing requirements within their specific circumstances. Worthy of note here is that the current bureaucratic structure of healthcare provision will likely influence the response of health professionals in a way that inhibits practice within a narrative model of care and compliments the dominant model of diagnosis and 'cure'. However, I argue that stories are a powerful way of making the invisible visible and of finding solutions. Narratives have the potential to reveal diagnostic and therapeutic options, provide a medium for the education of both patients and health care professionals, and expand and enrich the research agenda. Understanding the ways in which patients interpret the disruption posed by epilepsy and the efforts they make to create continuity would likely facilitate the delineation of practice and help to fine tune service delivery. Through analysis of stories the linkages between meaning and functional ability in the context of everyday life can be identified and used to inform the practice of epileptology from diagnosis to long term care. Supplementing the existing approaches to epilepsy care with narrative-informed practices, sensitised to the peculiarities, effects, and symbolic meanings of epilepsy, may valuably extend the impact of traditional medical therapy, enabling healthcare and psychosocial interventions(s) to be much more responsive to individual need. The potential applications of a narrative model of care are outlined in Figure 9 and discussed below. What is imperative however is the need to ensure that all those involved are reminded that persons with epilepsy live in subjective worlds as much as they are affected by objective conditions; and that intervention needs to take account of this.

Figure 9: Potential applications of a Narrative Model of Care

Application of a narrative model of care	Potential benefits of a narrative approach
Diagnostic encounter	• The phenomenal form in which patients experience ill health is brought to the fore • Allows for the construction of meaning, the interpretation and integration of disruption and provides insight into how people with epilepsy constitute their identity following diagnosis • Offers insight into how individuals adapt to their condition and as such may supply useful cues and categories for educational intervention • Promotes understanding between patients and health professionals
Clinical treatment encounters	• Promotes interactions with individuals – *empathetic witnessing* (Kleinman, 1988 p.54) • Promotes a willingness to allow the patient to be the expert of his / her own narrative • Promotes listening skills and a relinquishment of power – so fosters patient collaboration and inclusion • Promotes mutual trust between health professional and patient • Embedded in context - thus promotes a holistic approach to inform condition management • Enables the examination of specific events / problems / critical incidents and people's responses to these • Informs thinking about interventions and programmes of interventions • May suggest or precipitate additional therapeutic options
Educational encounters with patients and practitioners	• Essential pre-requisite for understanding experience and for enhancing the legitimacy and relevance of advice giving • Are often memorable • Facilitates peer led support • Health professional reinforces psychosocial skills in patient • Encourages self-reflection on benefits of behaviour change • Promotes the process of empowerment

Commissioning encounters	• Provide an active voice and role in the acquisition of healthcare services and policy development • Embedded experience pinpoints gaps in service provision

8.4.2.1. The provision of psychosocial intervention

Within the context of this study, it is worth reminding ourselves of an earlier comment articulated by Brenda, *"It's not just the actual seizures; it's living with epilepsy".* This sentiment was reflected in the narratives of other participants within this group, and serves to challenge the wisdom of the existing medical model of care. My own findings suggest the experience of living with epilepsy is much more than symptom and seizure management. The impact on a patient's wellbeing, overall quality of life and potential effect of epilepsy on their sense of self, requires epilepsy management involving a team of skilled healthcare professionals – including specialist nurses, counsellors and clinical psychologists (Johnston, 2010). The provision of psychosocial intervention to address wider patient issues such as epilepsy co-morbidities, employment, social interactions and stigma, and family issues, is likely to be of value for individuals with epilepsy and for their family members. It should therefore be an integral aspect of epilepsy service provision; and not just offered, as indicated in NICE guidelines (2012), when seizure control is inadequate.

Listening to stories of patients' illness provides practitioners with the opportunity to address specifically issues of patients' experience of illness. For example, it is possible, through the medium of narrative, to examine specific events, problems or needs, and critical incidents, as well as gain insight into how individuals respond to them. This brings to the fore other aspects of illness experience, such as coming to terms with disrupted identities, that have tended to be overlooked previously. In the context of the current study, the narratives of Ricky and Fran, telling of lives that are measured and organised, of self-imposed social restrictions employed as tactics to avert seizure occurrence, and of the subsequent guilt each felt about how their epilepsy impacted on the lives of other family members, serve as narrative signposts for psychosocial intervention(s). Here, in collaboration with health practitioners, patients can identify for themselves what are the areas of their lives they feel are most under threat by their epilepsy and in how far different care options, including self-management decisions and tasks, are linked to meaningful

outcomes (Aujoulat, et .al, 2007). In this way stories can be used to inform on individuals' psychosocial performance and the trajectory of personal transformation in achieving continuity and coherence in their lives. Patients can become actively involved in negotiating their care goals and as a result of this empowerment process will likely understand better their condition and fit it in to their life in a more positive manner (Anderson et.al, 1995). A successful process of empowerment occurs when patients come to terms with their threatened security and identity, which as Aujoulat and colleagues (2008) suggest will likely be facilitated by health-care providers through the use of narratives.

8.4.2.2. The provision of educational intervention

My participants' stories also carry implications for knowledge and understanding around epilepsy care and information provision. NICE guidelines (2012) make explicit the importance of patients *"being given appropriate information before they make important decisions (for example, regarding pregnancy or employment)"* (see section 1.3.). The purpose of such information provision is to enable patients to make informed choices and to empower them to manage their condition. However, participants within this study often spoke of situations where this was not the case. As examples, Jessica spoke of a lack of information and support in relation to her medication regime and Ricky felt overwhelmed by the risks he perceived to be associated with his condition. In searching for answers, participants often found themselves having to come to terms with the limitations of medical knowledge and conflicting advice (see Chapter Five).

As well as recognising the need to accept a potentially stigmatising diagnosis, educational interventions aimed at teaching and supporting people with epilepsy, for example, to identify and manage seizure triggers, implement strategies to help them to remember to take their medication, implement precautions to minimise risk during seizures, and decide what to tell others to do during a seizure (Dilorio , et. al, 1996; Fraser, et. al, 2011; Risdale, et. al, 2012) will likely lead to better self-management and re-establish a sense of continuity. The narrative framework identified in Chapter Five highlights the common areas of concern for people with epilepsy throughout the trajectory of their condition. As such it provides insight for the content and timely intervention of behaviour change programmes. As patients become aware of the potential life changes they must come to terms with in order to adjust to their condition, such programmes can be responsive to contextualised experiences and need. Patient-centred interventions, based on the

principles of experiential learning, have the capacity to be empowering (Aujoulat et. al, 2007). In particular, the experience of women of childbearing age reinforces the importance of the NICE (2012) guidelines for adequate and timely information provision to women to reduce misunderstanding and promote informed decision making.

8.4.2.3. The Epilepsy Nurse Specialist role

A deficiency in existing healthcare provision for adults coping with epilepsy has been highlighted by participants' narratives within this study group. In particular, these stories revealed a lack of structure and an inability to meet the patients' needs for information and support to cope with their epilepsy. For example, Ricky noted how: "*there is no-one to say would you like to come in and we can talk about how it's affecting yer"?* As senior registered nurses with neurological training and clinical experience, epilepsy nurse specialists are well situated to listen to their patients and to provide a bespoke package of care tailored to meet individual needs (Kwan et al, 2000). This could be achieved by:

- Providing accurate information and advice to people with epilepsy and members of their family in the management of their epilepsy; determined by listening to patient experiences and concerns throughout the trajectory of their condition and their life. This information likely includes:
    - *Medical aspects* – information related to tests, diagnosis, medication, prognosis, family planning and first aid care
    - *Social aspects* – information related to safety, leisure activities, employment, driving, coping with lifestyle change, self-help groups
- Responding to patient stories by offering counselling and support as necessary. This can be tailored to individual need, with the aim of reducing psychosocial hardship and improving the patient's quality of life.
- Promoting self-management by working closely with patients to help them recognise, through their stories, factors that impede psychosocial wellbeing. Working alongside the individual to identify strategies to promote change will empower them to take control in the management of their condition (Aujoulat et al, 2007; 2008).
- Interdisciplinary liaison to identify and co-ordinate the multidisciplinary healthcare needs of the individual with epilepsy. This is essential, for as Johnston (2010) argues, there is a need to strengthen the working relationships between the allied epilepsy specialities as a means to promoting patient trust and confidence in their

epilepsy team and clinician. This in turn would lead to a more fulfilling doctor-patient consultation.

However, evidence to support the effectiveness of epilepsy nurse services is conflicting. For example, findings from controlled clinical trials suggest that epilepsy patients cared by a nurse are well informed and have a high degree of satisfaction (Greenhill et. al, 2002). Structured epilepsy nursing and nurse-led intervention programs in epilepsy care were also found to significantly improve quality of life in adult patients with uncontrolled epilepsy in a study conducted by Helde and colleagues (2005). Conversely, a number of systematic reviews of specialist epilepsy services showed no evidence of reduced seizure frequency or severity and no effect on quality of life, though they were found to be less expensive (Meads et. al, 2002). Similarly, a Cochrane Review conducted by Bradley and Lindsay (2003) found no convincing evidence that specialist epilepsy nurses improve outcomes for people with epilepsy overall. Important outcomes (e.g. seizure frequency, psychosocial functioning, knowledge of epilepsy, general health status, work days lost, depression and anxiety scores) showed no significant improvement. Neither was there any evidence to suggest that newly diagnosed patients whose knowledge about their condition is poor may improve their epilepsy knowledge scores after nurse intervention. While it is clearly plausible that specialist epilepsy nurses could improve quality in epilepsy care, there is currently insufficient evidence to support this assumption, as the present research base is small.

Two observations, which highlight a need for change, seem relevant here. Firstly, there is the issue that specialist nurses are at times confronted by blurred professional boundaries. Professionals allied to medicine who work closely with medical practitioners often adopt discursive practices that reflect the values and characteristics of the dominant medical model. I argue that while the specialist nurses may claim to practice in a different relationship with patients from their medical counterparts, they often work closely with their medical colleagues. In such circumstances, and within current healthcare infrastructures, they may take on the attributes associated with medical dominance, such as, for example, applying diagnosis to symptoms and prioritising physical over psychosocial care. This in turn, I argue, minimises opportunities for them to take a more holistic approach to care and to work within the 'narrative model'. Consequently, the focus on individual experience, the time afforded to listening to patient stories and to responding appropriately throughout the trajectory of their patient's condition becomes diluted.

Secondly, further research is needed to investigate the effectiveness of specialist epilepsy nurse intervention. Currently there is insufficient evidence to demonstrate the superiority of *any* existing care model for producing better health outcomes (Meads et. al, 2002; Bradley & Lindsay, 2003). This, coupled with the findings from the current study of participants' dissatisfaction with their medical care and treatment, and the provision of appropriate information and support promotes the need to evaluate a narrative model of care as a means to alleviating suffering and promoting adjustment. The common themes identified in Chapter five are enlightening in that they provide a framework for understanding the journey of epilepsy. The framework, represented by the four components of the epilepsy plot line - the process of discovery, searching for a cause, negotiating uncertainty and risk, and, striving for control - provides commonalities in the 'life with epilepsy' stories. Such stories can be used to provide insight in how people with epilepsy constitute their identity following diagnosis and offer insight into how they self-manage and adapt to their condition. This may help health professionals to better understand the challenges of living with epilepsy and to translate this understanding into intervention strategies to help patients successfully integrate epilepsy management into their lives (Aujoulat et al, 2007; 2008).

8.4.2.4. Commissioning of epilepsy services

Despite the progress made in recent years, there remains a clear need for effective commissioning of epilepsy services to further improve management of epilepsy, access to care, quality of care and overall outcome for patients with epilepsy in the UK (Epilepsy Action, 2012). Johnston (2010) argues that given the overlap in co-morbidities the development of epilepsy liaison posts and specialities such as psychiatry, psychology and counselling posts is warranted. However, a recent report - *Epilepsy in England: the local picture* – commissioned by Epilepsy Action (2014a) highlights that disappointingly, epilepsy services planning generally remains poor, with only 10% of Clinical Commissioning Groups having a written needs assessment in place for people with epilepsy.

The application of patient narratives as a demonstration of service need could usefully serve to inform commissioners of current gaps in epilepsy service provision. Such accounts convey experience in the context of everyday life, highlight the concerns and priorities of those with epilepsy and reveal opportunities for service interventions. This use of a narrative approach in the commissioning of services within a care institution would require

not only the voluntary involvement of those living with epilepsy but also the support and endorsement of healthcare professionals. It may also require institutional validation of the usefulness of such an approach. However, the postmodern view embedded in a narrative approach renders the production of 'hard data' to prove its efficacy, difficult. Further research for assessing the effectiveness of narrative applications may go some way to addressing such organisational concerns. In this regard, the application of improvement science which is focused on developing and testing service improvement methodologies and putting them into practice, may prove useful (Granville, 2006; Greenhalgh et, al. 2004). These methodologies promote what has been termed 'experience based design' (Bevan 2005). The focus is on patients working in partnership with front line staff to design new models of care based on their experiences. It concerns the whole experience, from a user perspective (Bevan 2005) and maps patient 'touch points' – for example, in the words of Jessica: "*…I was put on medication but no one went through the side effects of the medication, no one went through, you know, how to sort of manage it"*. Patient stories and storytelling are used to give insights into the strengths and weaknesses of present services and how they might be redesigned in the future.

Similarly, The Epilepsy Society (2013) is committed to engaging with policy makers and patients in order to influence the development of National Health, social care and welfare policy. Conversely, it is also important for health professionals to promote the role of epilepsy patient groups and charitable organisations, counsellors and volunteers as they have the potential to play an important role in providing support, education and information for people with epilepsy and their families (Johnston, 2010). As an example, Epilepsy Action launched a new campaign in 2013 to raise awareness among members of the public (Epilepsy Action, 2014b). As a result, Epilepsy Action report achieving 2,042 pieces of coverage across the printed press, online publications and television and radio during 2013; this coverage, they argue, provided over 35 million people with the opportunity to learn more about epilepsy. In addition, online e-learning modules have been made available to healthcare professionals and to the general public as a means to facilitate learning about epilepsy.

8.5 Conclusions

Seizure control is important and inevitably forms a significant aspect of epilepsy management but other considerations are of equal importance. In many of the stories told by participants, resistance to standardised medical guidelines can be observed. I would argue that many of the issues identified - living with fear, identity and independence losses, and certain aspects of significance for stigma - require greater consideration by healthcare professionals if reconciliation of the existing tensions between holism and homogenised epilepsy practice are to be effectively addressed and treatment success achieved.

By using a narrative approach to explore the experiences of living with epilepsy I have provided evidence to challenge the wisdom of limiting care to managing epilepsy within the existing medical model. My own findings suggest the experience of living with epilepsy is more than symptom and seizure management and health professionals should aim to address other factors that likely present themselves as being of more immediate or equal concern to patients. The impact of epilepsy on sense of self and wellbeing and overall quality of life and the potential impact of symptomology require involvement of a team of specialised healthcare workers and counsellors who are able to address the wider issues around the meaning of epilepsy and living and coping with epilepsy. These include, for example, epilepsy co-morbidities, social interactions and relationships, stigma, employment and driving.

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LIST OF APPENDICES

Appendix 1 – Literature Search Strategy

Search Aim

To identify primary research or reviews in relation to various 'bodies of literature' relevant to the study of epilepsy, stigma, chronic illness, postmodernism, social constructionism, and qualitative research and narrative research methods.

Selection Criteria

References for the various literature reviews were identified with the aid of a search strategy and focus–specific search terms to enable the conduct of systematic computerised searches of relevant journals, databases and web sites. Secondary references that met the inclusion and exclusion criteria were identified from retrieved articles. To reduce the effects of a biased review grey literature resources were also accessed for relevant information related to each of the searches. 'Experts in the field' networks; including clinical and non-clinical academics were contacted as a means of identifying related information including conference papers, unpublished and ongoing research:

- Allied and Complimentary Medicine - 1985 onwards
- British Nursing Index - 1985 onwards
- CINAHL - 1982 onwards
- Epilepsy Action via WWW - Current
- Epilepsy Foundation via WWW - Current
- Epilepsy Professional via WWW - Current
- Epilepsy Today via WWW - Current
- Google Scholar via WWW - Current
- Index to Thesis (GB/Ireland) - 1796 onwards
- Interdisciplinary - Dissertation & Thesis Abstracts (US) - 1861 onwards
- International Bibliography of the Social Sciences - 1951 onwards
- Kings Fund Database -1979 onwards
- National Centre for Research Methods via WWW – Current
- National Electronic Library for Health – 2004 onwards. To include:
    - HTA, DARE, EED, Cochrane Library
- NHS National Research Register - Current
- National Society for Epilepsy via WWW - Current
- National Institute for Clinical Excellence via WWW - Current
- National Service Framework via WWW - Current
- Ovid MEDLINE (R) - 1966 onwards
- ProQuest - 1938 onwards
- PsychInfo - 1972 onwards
- Science Direct - 1997 onwards including:
    - Archives of Psychiatric Nursing
    - Health Policy
    - Epilepsy & Behavior
    - Qualitative Health Research
    - Narrative Inquiry
    - Social theory and Health
    - Sociology of Health and Illness

    - Social Science and Medicine
    - Seizure
- The Department of Health via WWW - Current
- World Health Organisation via WWW - Current
- *'Experts in the field'* networks - Ongoing
- Secondary References - Ongoing

Applied Limits

The following database limits were applied:

- Research or Reviews
- Peer-reviewed Journal
- Human
- English Language
- Duplicates Removed

Inclusion Criteria

Articles were retrieved if their content focused on any of the following criteria:

- Adults
- Adolescents
- Male
- Female
- Policy
- Strategy
- Guidelines

Exclusion Criteria

Articles were rejected were the primary focus related to:

- Non-illness stigma e.g. ageism, sexism, racism
- Children

Key Words and Combinations

Key words and combinations of terms were used with Boolean operators and truncation options. This approach to searching was undertaken to ensure both the specificity and sensitivity of search criteria for each of the 'bodies of literature' and to ensure that the optimum numbers of relevant papers were identified and retrieved. Key word combinations varied in response to their scope and definition, identified within each of the databases.

Bodies of Literature and Associated Search Terms and Combinations

Epilepsy and Stigma:

- Stigma$ OR stereotyp$ OR prejudice AND
- Epilep$

- Mental Illness OR mental health
- Anti-stigma OR stigma-reduction OR stigma prevention
- Attitude$/Behavi$
- Culture- cross cultural OR customs OR beliefs

Epilepsy as Chronic Illness

- Epilep$ (to include: Epilepsy- seizure; absence; epileptic; tonic-clonic; episode; partial seizure; generalised seizure; epileptic convulsion; fit; epileptic attack; petit mal; status epilepticus; sub: aura AND epilepsy; déjà-vu AND epilepsy)
- AND ‗chronic illness' OR –chronicity

Chronic Illness

- AND Loss
- AND Coping- cope OR Struggle OR Resilience (psychological) AND
- Psychological Impact OR Psychological Adjustment OR Emotional Adjustment OR Social Adjustment OR Psychosocial Adjustment
- Quality of life- sequelae OR Trajectory OR Well Being OR Life Satisfaction

Epilepsy or Illness Narratives

- Epilepsy AND Narrative(s) OR Stories OR Story-telling OR Narration OR Narrative Act OR Life Story OR Biography
- OR Illness narratives
- AND Lived-experience
- AND Biographical disruption
- AND Biographical reconstruction OR legitimisation OR biographical reinforcement
- AND Identity

Qualitative methodology

- Postmodernism
- Social constructionism
- Qualitative Methods
- Descriptive
- Meaning Making
- Narrative Analysis
- Phenomenology
- Grounded Theory

Criteria for Retrieving Articles

- Research, reviews and information, which met with the inclusion criteria and were available in full text format, were downloaded from the relevant web sources
- Articles and books available through the Liverpool University Libraries and the British Library were also retrieved
- Secondary references from retrieved articles were reviewed and the same set of inclusion and exclusion criteria applied. Secondary references matching the inclusion criteria were retrieved.

Appendix 2 – Interview Guide

1. Introductory statement / question

We hear a great deal about epilepsy in terms of the medical management of the disease but far less about how the condition affects the daily life of a person with epilepsy from the point of view of a person with epilepsy. This is why I am interested in hearing ***your*** *story* of *your life with epilepsy…*

I would like to begin our conversation by asking you to:

"Tell me the story of your epilepsy from the moment you realised or were told that something was wrong with you"

2. Clinical manifestations of the condition

- How did you first notice something was wrong?

Probe: When? Where? Seizure? Medical identification?

- Pattern of occurrence

Probe: How often? How bad? What happens? Trigger? Warning? Coping with uncertainty?

- How do you feel during / following an incident?

Probe: How do they handle situation?

3. Health seeking processes involved

- Where did you learn what you know about epilepsy?

Probe: Medical diagnosis, if so by whom?

- What type of treatment for epilepsy?

Probe: Medication, type, duration and frequency? Experiences of medication, side effects? compliance?

- Level of satisfaction with the treatment received?

Probe: How often see Dr? *Degree of involvement in the management of own condition? Alternative methods sought i.e. homeopathic, if so, type, when, from whom, why?*

- What aspects of care could be improved?

Probe: Formal/informal? How might this be achieved?
Probe: When? Where? Seizure? Medical identification?

- Pattern of occurrence

Probe: How often? How bad? What happens? Trigger? Warning? Coping with uncertainty?

- How do you feel during / following an incident?

Probe: How do they handle situation?

4. Daily life circumstances and activities of people with epilepsy

- Affects of epilepsy on day-to-day living?

Probe: Schooling/educational opportunities, ability to work/employment opportunities, if so, in what way?

- Affects of epilepsy on ability to interact with others?

Probe: Helped or hindered ability to socialise/establish and maintain friendships, if so, in what way and why? Opportunities for marriage/marital situation/ability to have children, if so, in what way and why?

5. Perception of role within society/relationships with others

- How did finding out you have epilepsy affect your life?

Probe: Think about how life was before they found out about condition – medical/social impact of condition. What changes have had to be made and why? Proud of achievements, what and why? Disappointments, what and why?

- How do you think having epilepsy has affected your family/friends?

Probe: Did family/friends behave differently once they found out, if so in what way? Does the attitude of family/friends affect your coping/management of epilepsy, if so in what way and why?

6. Perception of self in relation to epilepsy – past, present, future

- What does having epilepsy mean to you?

Probe: Sense of being different, if so in what way? Gains from having epilepsy - strengths, resilience, pride, positivity, and opportunity? Hampered life in any way - feelings of guilt, frustration, annoyance, victim of prejudice and lost opportunity?

- Can you tell me if you think having epilepsy is worse than having another type of chronic disease, if so, why?

Probe: Concealment, What do they believe other people, who do not have epilepsy, think about it?

- Have their views on seizures/epilepsy changed over time, if so in what way?
- Has having epilepsy affected your hopes and aspirations for the future? If so, in what way?

Probe*: Encourage issues to be discussed within domain role(s); i.e. male, female, mother, lover, worker etc…*

7. Coping strategies employed

- How well do you feel you cope with the effects of having epilepsy?

Probe: What interventions support adaption, information management, education of self and others, participation in self-help groups, isolation?

- What would you like to see changed to assist with coping?

Probe: legislative, societal, family/friends, and personal change

8. Interview de-brief

Is there anything else you would like to tell me about what it is like to have epilepsy?

Are there any questions you would like to ask me in general or specifically in relation to the conduct of this interview?

Thank you so much for your time today - your responses will help greatly in raising awareness and understanding about what it means to live with epilepsy

Discuss support mechanisms available to participants:

- Access to clinical psychologist to discuss concerns
- Hand out leaflets - if wanted
- Provide web details for Epilepsy Action and local epilepsy support groups - if wanted
- Explain about study Newsletter - confirm whether they wish to be on mailing list

Appendix 3 – Annual Participant Research Newsletter (Example Edition: December 2006)

Epilepsy Narratives

Research Newsletter

December 2006 Issue 2

Special Points of interest:

- Personal Experiences from the 10th European Congress on Epilepsy and Society
- Understanding Narrative
- Poster Presentation
- Research Update
- Associated Research Activities

Dear Participants!

Welcome to Issue 2 of this Newsletter.

I hope you find the information of interest - should you have any comments please do not hesitate to contact me.

Many thanks to you all for your continued support and very best wishes for 2007

Dee Snape

Personal Experiences from the 10th European Congress on Epilepsy and Society

I was delighted to have my study poster *Epilepsy Narratives: the difference in being different* accepted for presentation at the 10th European Congress on Epilepsy and Society held this summer in Copenhagen. [turn to page 2 to see a mini version of the poster presented!] Firstly because the theme of the meeting 'Better Quality of Life for People with Epilepsy' reflects my own research objectives but more importantly because it provided an opportunity to discuss my work with those directly affected by the condition, namely people with epilepsy and their family members.

Following the Opening Ceremony held at Copenhagen City Hall delegates were able to participate in two days of activity. Discussions focused on the individual as well as exploring the role of political action and Organisations in facilitating improvement and change in the lives of people with epilepsy. A wide range of topics were discussed including the need to establish national guidelines to reduce both the variation in clinical care and access to care for people with epilepsy throughout Europe.

For information or an entry pack for the *Freedom in Mind* artistic project contact info@freedominmind.com

This conference also saw the launch of the 'Freedom in Mind Experience'; an exhibition to encourage people with epilepsy to express their feelings about what 'freedom of seizures' means to them. I was very moved by the poetic accounts and art work on display which provided an excellent medium through which to enlighten others about what it means to have epilepsy from the perspective of someone with the condition.

Apart from improving my own knowledge I particularly enjoyed this meeting because of its emphasis on discussion and sharing of information. This was achieved through platform presentations, question and answer sessions and interactive workshops and I look forward to meeting colleagues and the many new friends I made at the next conference in 2008.

Finally, many thanks to the IBE for their Conference Bursary Travel Award which enabled my attendance.

Understanding Narrative

Many people have asked '*what is narrative inquiry?*' Well having studied the subject in some depth it has become clear that a single definition of the term is impossible. This is because there are a variety of narrative styles and methods of analysis covering almost every discipline and profession. What is clear however, is that the interest in narrative has become widespread within healthcare.

In brief narrative inquiry is the process of gathering information through storytelling. Narratives can take a number of forms but in this study about the lives of those with epilepsy they are extended interviews that have been recorded and transcribed.

As with other forms of qualitative research the story segments selected for narrative analysis

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Dee Snape , Research Associate, Division of Public Health, University of Liverpool, UK dsnape@liverpool.ac.uk

Epilepsy Narratives: the differences in being different

Purpose

- To explore the nature of having epilepsy & issues of related stigma from the perspective of people with epilepsy
- To enhance understanding about the impact of this condition on daily living & life trajectories
- To contribute to stigma theory & to the debate on the need for an holistic approach to care

Methods

- Systematic literature review
- Qualitative methods:
  - *Ethnography*
  - *Serial life history interviews; adults with epilepsy*
  - *Paradigmatic & narrative analysis*
  - *Researcher observations*
  - *Participant validation*

Emerging narrative dimensions of the epilepsy experience

Disruption & difference: *not a static concept; played out differently throughout & across the lives of respondents; linked to personal, family & social values & expectations*

I might have epilepsy but I'm still me…Its not like me to get scared about that [seizures] *I was more worried about what people would think of me…when I went back people seemed pleased to see me but I felt like an outsider*

Coz I'd been off work for a while I mentioned to her [neighbour] I had epilepsy. Oh God! I didn't want anyone to know but I didn't want her to think I was skiving…I'm not skiving. I've worked all me life. I'm off for a genuine reason

Striving for control & normalcy: *expressed in terms of bodily control of seizures; independence of self; notions of progress*

It's like having your wings clipped…when you've got that independence back, making your own choices it does make a hell of a difference

Healthcare experience: *medical emphasis on diagnosis & symptom control; perceived lack of information about 'how to manage epilepsy'*

He said, right its epilepsy, you'll probably be on medication for the rest of your life!

Holistic nature of epilepsy: *not just about 'bodily knowledge' but the affects of bodily knowledge on attitude & the meaning of everyday life*

I don't know what it would be like living without epilepsy now…it would be a big step to be cured…I'd have to get used to not having it

…confused & worried because I didn't know what was going to happen to me over the years

Its not just the actual seizures its living with epilepsy

Conclusion

- **Analysis of pilot study data confirm the usefulness of Polkinghorne's[1] two types of narrative inquiry in identifying categories & sub-categories & in guiding the process of 'core story' production; this approach will be replicated in the main study.**
- **The use of narratives as a vehicle for the construction of meaning has the potential to inform understanding of the divergent nature of *life with epilepsy* beyond the biophysical.**

[1] Polkinghorne DE (1995) Narrative configuration in qualitative analysis. In: *Life History & Narrative*. Hatch JA & Wisniewski R eds., The Falmer Press, London, p5-23.

Acknowledgement: Research partially funded by Epilepsy Action

Understanding Narrative

are open to various interpretations. Stories do not 'speak for themselves'; their structures are culturally determined, thus individual researchers may arrive at different conclusions regarding the structure, shape and *meaning* of stories. However providing the analysis is undertaken responsibly and remains faithful to the data and method, then the conclusions drawn can be accepted as valid interpretation.

Puzzling over how to think narratively I reflect on memories across time, imagine myself amidst the stories and try to interpret new ways forward in old and new story lines. In this way narrative inquiry offers me a way of understanding experience as well as how I might research it.

I hope that through the interpretive activities of both myself as researcher and each of you as participants, the process of co-participation and co-construction of stories, which is inherent in narrative inquiry will reveal a circular way of understanding experience.

As I inquire into what it *means* to study the experience of living with epilepsy, the concepts of culture, health, experience and life become intertwined.

What matters to people keeps getting told in their stories of their lives

A typical narrative framework

The narrative approach provides an organisational structure which focuses on a 'core narrative' or a skeleton plot through four categories:

Orientation - describes the setting and the character

Abstract - summarises the events or the incidents of the story

Complicating Action - offers an evaluative commentary on events, conflicts and themes

Resolution - describes the outcome of the story or conflict.

Questions can be posed on issues previously raised and further stories offered.

The strength of narrative inquiry is its potential to illustrate a range of stances; cultural, sociological, psychological, biographical and therapeutic perspectives.

In the context of *the lived experience of epilepsy*, narratives can offer a user perspective on health and illness, illness experiences, service delivery and influences of policy.

Within this research your narratives will act as sources of knowledge or 'evidence' about needs and issues in the practice and service delivery of epilepsy care.

Narrative is now viewed as one of the fundamental ways in which people make sense of past experiences and share them with others

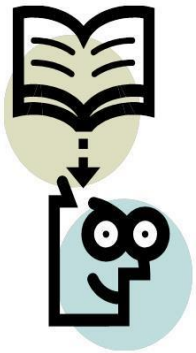
Research Update

I know for some of you it has been a while since we last spoke, but I haven't forgotten about you, *honestly!*

I have been meeting with other participants and listening to their experiences.

I now only have about 4 more people to recruit to the study and this will be completed by the end of March 2007.

Following these initial interviews I will be back to talk with you again - with your permission of course!



The analysis from the pilot phase of the study is well underway and I hope to return to you all shortly with an overview of my analysis of your stories.

This will provide us with the opportunity to clarify my findings to date for both content and meaning and I look forward to meeting with you all again in due course.

Epilepsy Narratives

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You can e-mail me!

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THE UNIVERSITY of LIVERPOOL

Kenneth Kaufman, a clinician who's dedicated his professional life to the treatment of epilepsy, understands only too well the consequences of varied treatments over the lifetime course of his own epilepsy. He offers this poetic reflection as a reminder to other clinicians that quality of life might not always mean total seizure control.

Enough Intervention

Of the many patients that we have seen
How oft we wonder what might have been
We witness uncontrolled seizures in adult and child
And hear argued that surgical intervention is mild
The empathy that we feel
Can make their seizures seem so real
But objective distance
Taught us medical persistence
Medicines and surgeries have a price
Decisions should not be made with ice
Our goal is seizure control but at what cost
Does anyone think of quality of life lost?
Weight gain, confusion, dizziness, fatigue, depression
Should teach physicians and surgeons a much needed lesson
Perhaps the seizures we clinicians fear
Does not address what a patient holds most dear
Sometimes one intervention less
The patient answers would have been best

Associated Research Activity

Publications

Jacoby A., **Snape D.**, Baker G. (2005). Epilepsy and Social Identity: the stigma of a chronic neurological disorder. *The Lancet Neurology,* 4 (3):171-78.

Snape D., Jacoby A., Baker G. (2005). Stigma and social Issues In: *Atlas - Epilepsy Care in the World* , WHO p78.

Jacoby A., **Snape D.**, Baker G. Social Aspects: Epilepsy, Stigma & Quality of Life In: Engel J, Pedley TA, eds *Epilepsy: A Comprehensive Text Book*. New York. Lippincott Raven. Ch218.

Presentations

Snape D., (2006) *Epilepsy Narratives: the differences in being different*. 7th European Conference on Epileptology, Helsinki.

Snape D., (2006) *Epilepsy Narratives: the differences in being different*. 10th European Congress on Epilepsy and Society, Copenhagen.

Awards

Postgraduate Research Bursary Award (2005/2006) Sponsor: *Epilepsy Action.*

epilepsy action

Research Travel Scholarship 2006) Sponsor: *International Bureau for Epilepsy*

Appendix 4 – NVIVO coding nodes

[Altered] sense of self
• Dependency • Perception of self in relation to others • Role identification • Self confidence • Self-consciousness [and / or] visibility • Self-esteem [and / or] self-worth • Sense of [changed] identity • Sense of burden to others • Sense of failure • Sense of purpose
Clinical manifestations
• Aura or unpredictability • Chronicity • Frequency or severity • Post-op • Pre-op • Onset • Post-seizure state • Potential triggers • Symptoms
Disclosure management
• Consequences of disclosure • Stigma [-ve outcome] • Exclusion • Support [+ve outcome] • Disclosed to whom • Disclosed to college [teachers & friends] • Disclosed to family • Disclosed to others • Disclosed to school [teachers & friends] • Disclosed to work • Reasons for [non]disclosure
Epilepsy or seizure management strategies
• Diet • Exercise • Mental stimulation • Other
Future
• Fear • Goals [and / or] ambitions [and / or] aspirations • Hope • Positive outlook • Uncertainty

Health seeking process
• Access • Diagnostic process • Effectiveness • Satisfaction • Side effects • Treatment regime or justification or choice
Impact of epilepsy
• Education • Emotional • [Restrictions] activities of daily living [and / or] socialising • Anger • Fear • Felt [and / or] enacted stigma • Isolation [and /or] lack of support • Relationship with others • Shame [and / or] embarrassment [and / or] guilt • Upset [and / or] anxiety [and / or] depression • Family • Mental [and / or] psychological • Physical • Work [and / or] employment
Knowledge / understanding / belief
• Causes or attribution • Others • People with epilepsy
Lay descriptor of epilepsy / metaphor
Religion / spirituality / meditation
Response of others
Management of response(s) Perception
Response to / impact of diagnosis
For others For people with epilepsy [non]Acceptance Anxiety - fear for future Disclosure Felt stigma Isolation Metaphor
Sense of control or independence
Determination
Utilisation of external support

Appendix 5 – Participant Letter of Introduction

[To be printed on University of Liverpool Headed Paper]

[Insert Name]
[Address 1]
[Address 2]
[Postcode]

Correspondent:
Office Telephone: [redacted]
Mobile Telephone: [redacted]

[Insert potential participant ref no]

[Insert date as postmark]

Dear [Insert Name]

Re: Invitation to Participate in a Qualitative Research Study

I am a Doctoral Student, studying within the Division of Public Health at the University of Liverpool. As part of my research I am interested in talking to people with a history of epilepsy. Some people think epilepsy is not just a medical condition but also a social label, and the way in which a person might deal with this label and the stigma that is sometimes associated with it has an inevitable impact on their wellbeing. For this reason I wish to explore the way a person's circumstances and the nature of epilepsy influences the effect that it has on them. This is important because understanding how people experience epilepsy has implications for both research and for health care practice.

This initial letter has been forwarded to you via [*gatekeeper details*], who has agreed to help with this project by identifying people who might take part. At present, your details are unknown to me, ensuring confidentiality and your anonymity. You have been chosen because it was felt that you have an important contribution to make and I would be grateful if you could take a few minutes to read the enclosed information sheet (In-depth, face-to-face interview: Version 2), which explains the research study, and what your participation would involve should you agree to take part.

If, having read the enclosed information, you are not interested in finding out more about the project then you do not need to do anything and I would like to take this opportunity to thank you for your time.

If however, you feel you might be interested, please complete your details on the reply slip and return in the pre-paid envelope provided. I will then telephone you to explain more about the project and what your involvement would be should you decide to participate.

I would like to reassure you that there is no pressure upon you to participate. This is entirely your decision; any discussions undertaken throughout your 'decision making' period will remain confidential. Should you decide to participate we will ask you to sign a consent form, which you will keep.

Please feel free to contact [*insert gate keeper details]* who will be able to verify my details or you may wish to contact me directly if you require clarification of any of the issues outlined in this letter and the accompanying information.

Thank you for reading this information and for giving it your consideration.

Yours sincerely

Darlene A. Snape Doctoral Student/Research Associate

ENC's: As stipulated

First Name: **Surname:**

Male ☐ **Female** ☐ **Date of Birth:** _ _/_ _/_ _ _ _

Appendix 6 – Participant Information Sheet

[Print on University of Liverpool headed paper]

Information Sheet In-depth, Face-to-Face Interview

1. **Study title in full:**

The Differences In Being Different: a narrative analysis of the nature of epilepsy and its problems.

Short study title:

A narrative study of epilepsy and its problems (V2); 01/02/05

2. **Invitation**

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. **What is the purpose of the study?**

With an estimated 400,000 sufferers, epilepsy is a common health problem in the UK and one which about sometimes people have negative attitudes. Research suggests that being diagnosed with epilepsy not only involves learning to deal with the physical impact of seizures, but also learning to cope with the social and psychosocial consequences. However, knowledge of the exact way in which features of an individuals' circumstances influences the impact that their epilepsy has on them is not fully understood.

This is a qualitative study which involves collecting personal narratives (your story) from men and women suffering from epilepsy. The overall aims of this study are firstly, to explore the social and psychological experience of epilepsy and the meaning that an individual with epilepsy attaches to this; and secondly, to find out how much these experiences vary between individuals.

One of the outcomes of this study will be to share the knowledge gained with relevant groups (i.e. health professionals) to provide a framework for approaching individuals' problems holistically.

The total length of the study is 48 months.

4. **Why have I been chosen?**

You have been chosen because I am interested in hearing the life-stories of men and women, with a history of epilepsy who are not receiving clinical treatments other than anti-epileptic drug treatment.

5. **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you are a patient receiving medical care, a decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive

6. **What will happen to me if I take part?**

I will contact you and make an appointment to come and see you either in your own home or at a neutral place of your choice, at a time which is convenient to yourself. The interview will be audiotape recorded, with your permission, and will last approximately 2 hours. I would like you to tell me, in your own words, about your experiences, attitudes and beliefs about epilepsy. I will then meet with you again, at your convenience, to give you an opportunity to review the transcript of your interview. This will enable you to comment on the content and accuracy of any analysis of your story and allow you to comment further on any related issues. Approximately 10 people will be interviewed in this way.

7 **What are the possible disadvantages and risks of taking part?**

There are no physical risks associated with taking part in this study. Anything you tell the researcher will remain confidential and will only be discussed with researchers as part of the data analysis process. Any subsequent reports will not identify you by name.

Because they concern personal stories, interviews of this kind can stir up distressing feelings. Should this happen we will ensure support is available to you.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

8. **What are the possible benefits of taking part?**

There are not likely to be any immediate benefits for you, if you choose to take part in this study, although, you may appreciate being given the opportunity to tell 'your story'. However, the information we get will improve understanding about people's ideas and attitudes towards having epilepsy and this will help us to identify what needs to change in order to improve the lives of people with epilepsy.

9 **Will my taking part in this study be kept confidential?**

We will obtain your permission to allow restricted access to your medical records and to the information collected during the course of the study. All information collected about you during the course of the research will be kept confidential. All information about you will have your name and address removed so that you cannot be recognised from it. Your own GP will be notified of your participation in the study, but we will seek your signed consent before informing him/her.

10 **What will happen to the results of the research study?**

Following data collection, analysis and report writing will begin. I hope to complete this work by September 2008. Please let me know If you would like a copy of the results. Once again I wish to assure those taking part that they ***will not*** be identified in any report/publication.

11 **Who is funding the study?**

There is no formal funding to support this project. I am a Research Student, within the Division of Public Health at Liverpool University, undertaking this research as part of my Doctoral studies.

12 **Who has reviewed the study?**

This study has been reviewed and received approval from:

- The University of Liverpool - Faculty of Medicine Research Committee
- The [redacted] Research Committee [RG No: 013/05]
- Northwest REC2 – Liverpool Central Research Ethics Service [REC Reference 08/H1005/45]

13 **Contact for Further Information**

Should you require any further information, please do not hesitate to contact me:

Darlene A Snape,
Doctoral Student/Research Associate
The University of Liverpool
Division of Public Health
Liverpool
L69 3GB

A copy of this information sheet and a signed consent form will be given to you to keep.

Thank you for taking the time to read this information

Appendix 7 – Participant Consent Form

(*Print on Liverpool University headed paper)*

Patient ID:

INTERVIEW CONSENT FORM

Project Title: The Differences In Being Different: a narrative analysis of the nature of epilepsy and its problems.

Name of Researcher: Ms Darlene A Snape

Please initial box

I confirm that I have read and understand the information sheet dated 01/02/05 Version 2 for the above study and have had the opportunity to ask questions	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected	☐
I understand that the interview will be recorded and I will have an opportunity to comment on the validity and reliability of the transcript	☐
I understand that sections of my medical notes may be looked at by responsible individuals from [redacted] or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records	☐
I give permission for my General Practitioner to be notified that I have agreed to participate in the above named study	☐
I agree to take part in the above study	☐

_____	_____	_____
Patient	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 8 – Summary of Participant Data Collection Interactions

Participant name	Date	Data collection / interaction type	Focus / content	Approx time in minutes	Additional Comments
YOLANDE *	23/06/05	Informal interview	Developing rapport Study explanation Consent Key thread: Yolande expressed concern about her husband's illness	120	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	23/07/05	Formal interview	Epilepsy onset Health seeking Daily life circumstance – husband' health a priority Disruption to daily life has increased since his illness onset Husband's health more important than epilepsy	150	Formal interview tape recorded and supplemented by notes
	15/08/05	Informal interview to review transcript / emerging themes	Transcript / themes validated Further elaboration on disruption to daily routine since her husband's illness onset	65	Observational data recorded by hand written fieldnotes Expressed interest in receiving study newsletter
	12/12/05	Newsletter Issue 1 posted out & follow-up phone call	Husband's Alzheimer's disease is worsening Yolande needs support to care for him in the home Unable to participate further in the study	30	I gave Yolande my contact details in case she wanted to get back in touch At her request I mailed out details and leaflets about the Alzheimer's Society, and local support groups in her area
ALAN *	27/06/05	Informal interview	Developing rapport Study explanation Consent Key thread: Alan presents himself as a strong person; determined to show parents he can take responsibility for his treatment decisions	90	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion Away for 4 weeks of the summer. Alan will ring me on his return to organise interview
	15/08/05	Formal interview	Elements around onset & treatment but mainly draws on impact of epilepsy on social situation Pre-op and post-op self Strives for independance	155	Formal interview tape recorded and supplemented by notes
	13/10/05	Transcript sent out via post & follow-up telephone conversation conducted to discuss issues / themes	Transcript / themes validated Spoke further about the independence he had negotiated for himself with his parents	40	Now has evening job as events DJ – work Alan secured through advertisements on college notice boards
	12/12/05	Newsletter Issue 1 sent via post	N/A	N/A	N/A
	20/12/05	Alan telephoned me	Thanked me for the newsletter which he enjoyed reading General chat about his recent college experience / success	15	Requested further information about the study and copies of publications
	03/01/06	Copy of published paper sent via post	Jacoby, A., **Snape, D.**, Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. *Lancet Neurology*. **4**:171-78	N/A	No response
JESSICA *	27/7/05	Informal interview	Met Jessica at her office Developing rapport Study explanation Discuss consent Observed busy working environment Key thread: I don't let epilepsy stop me from doing things / competent in her role as worker	90	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion Lives with parents- Jessica does not want to be interviewed at home. She will make arrangements to meet me at a friend's house and let me know the details of our

					follow-up meeting
	19/09/05	Formal interview	Onset & treatment Dissatisfaction with medical encounters/ treatment Information seeking Impact of epilepsy on social situation and disruption to independence Renewed independence - positive lifestyle changes Advocate for self and others	180	Formal interview tape recorded and supplemented by notes
	10/10/05	Informal interview to review transcript / emerging themes	Transcript / themes validated Further elaboration on her need to "*speak out*" when people got things wrong about epilepsy Has been attending Mersey Region Epilepsy Association group sessions	90	Observational data recorded by hand written fieldnotes Expressed interest in receiving study newsletter and publications
	12/12/05	Newsletter Issue 1 sent via post	N/A	N/A	N/A
	03/01/06	Copy of published paper sent via post	Jacoby, A., **Snape, D**., Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurology. 4:171-78	20	Jessica telephoned to thank me for sending her the paper. She mentioned she was still attending the Mersey Region Epilepsy Association - invited by Prof. Baker to give a talk. Jessica said she was pleased to have been asked and was keen to speak
	04/12/06	Newsletter Issue 2 sent via post	N/A	N/A	No response
ASHLEY *	11/08/05	Informal interview	Developing rapport Study explanation Discuss consent Key thread: pre-post op self; previous sense of insecurity	60	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion Going into hospital for operation (not related to epilepsy) will ring me to arrange follow-up interview
	20/10/05	Formal interview	Onset & treatment Impact of epilepsy on family & social situation Disruption to self and to daughter's life style – couldn't go anywhere on her own. Pre-post op self – renewed independence positive lifestyle changes Has applied for a job as a carer	90	Formal interview tape recorded and supplemented by notes Ashley does not wish to see her transcript for review or to receive further communications
KAREN *	27/07/05	Informal interview	Met with Karen over lunch Developing rapport Study explanation Discuss consent Key thread: Karen liked the fact that she could talk about her condition rather than it being a study of numbers	90	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion Karen's dog is about to have puppies so she would prefer not to have the 2nd interview at the house. It was agreed Karen will ring me to arrange follow-up interview in a room at the university
	08/09/05	Formal interview	Onset & treatment Impact of epilepsy on social situation especially in relation to playing squash Disruption to self and to life style – surgical intervention turning point Pre-post op self – still remains competitive but has exchanged squash for dog agility competitions – recognised this activity as much less of a risk to her health re: sz occurrence Is able to drive again	100	Formal interview tape recorded and supplemented by notes Karen does not wish to see her transcript for review or to receive further communications
BRENDA *	16/08/05	Informal interview	Developing rapport	100	Observational data recorded by hand

			Study explanation Discuss consent Key thread: keen to portray herself as a competent worker and mother Serious physical injuries as a consequence of her seizure episodes In the process of negotiating early retirement		written fieldnotes / contextual descriptions used to inform future discussion
	16/09/05	Formal interview	Onset & treatment Poor response to AED's and surgery Impact of epilepsy on work / social / family situation especially in relation to son Feels guilty about having the condition and how it disrupts caring for her son Talks about the love of her job – guilty about having to take early retirement	180	Formal interview tape recorded and supplemented by notes Expressed interest in receiving study newsletter and publications
	14/10/05	Informal interview to review transcript / emerging themes	Transcript / themes validated Spoke further about her early retirement which has now been approved. Will use the time positively to improve her quality of life. Feels better and less tired when not working Has started keeping a diary as it helps her to *"organise"* her thoughts	70	Observational data recorded by hand written fieldnotes Expressed interest in receiving study newsletter and publication
	12/12/05	Newsletter Issue 1 sent via post	N/A	N/A	No response
	03/01/06	Copy of published paper sent via post	Jacoby, A., **Snape, D**., Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurology. 4:171-78		Letter from Brenda thanking me for the paper and explaining that since our last meeting she had joined a writing club which she enjoyed The club also helped her to make new friends
	04/12/06	Newsletter Issue 2 sent via post	N/A	N/A	No response
*** DENOTES PARTICIPANTS IN THE PILOT PHASE OF THE STUDY**					
RICKY	24/07/06	Informal interview	Developing rapport Study explanation Discuss consent Key thread: keen to portray himself as a competent father – concerned that he isn't fulfilling this role Having epilepsy is portrayed as a constant risk Stuck in a rut as nothing changes	60	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	15/08/06	Formal interview	Onset & treatment Poor response to AED's Refused surgery but has participated in many clinical trials in the hope for improvement in his condition. Impact of epilepsy on social / family situation especially in relation to childcare as a single dad Unable to work Reiteration of daily risk and being *"stuck"*	90	Formal interview tape recorded and supplemented by notes Does not wish review transcript or to receive study newsletter or publications
JUNE	27/07/06	Informal interview	Developing rapport Study explanation Discuss consent Key thread: worried what others will think when she has a blackout. Keeps herself to herself	60	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	17/08/06	Formal interview	Onset & treatment Impact of epilepsy on social / family	60	Formal interview tape recorded and supplemented by notes Does not wish

			situation Unhappy marriage Lost touch with son Withdraws in order to prevent embarrassment to others when she has a blackout Enjoys the quieter life		review transcript or to receive study newsletter or publications
WILLIAM	25/07/06	Informal interview	Developing rapport Study explanation Discuss consent Key thread: William was worried that he may not have a great deal to say – 3 year history of epilepsy which is well controlled Assured William his understanding and experience of epilepsy was important Left William with more time to think – it was agreed that I should ring him in a couple of weeks	50	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion William is a postman and said he might pop in to see me as he walks past the university on his round
	28/07/06	Informal chat	Following his postal round William called into my office for a chat William said he is now on a "*walking round*" having lost control of his vehicle during a seizure. Epilepsy well controlled Loves football which he talked about a lot!	25	William signed the consent and was happy for me to make a few notes about what we talked about –I assured him I wouldn't use any of the data until he was sure he wanted to go ahead with the formal interview
	11/08/06	Informal chat	William telephoned to check that I was in the office and called in to see me at the university	40	William talked about some of his work experiences with epilepsy and the support he had received from his employer and his colleagues. I made some notes and assured William that his experiences of epilepsy were very interesting and would definitely add to the diverse stories of epilepsy I had already collected William agreed to a formal interview and we arranged a date/time
	29/08/06	Formal interview	Onset & treatment Impact of epilepsy on working life & driving Employer & colleagues very supportive William has a positive outlook re: seizure control/remission	75	Formal interview tape recorded and supplemented by notes Does not wish review transcript or to receive study newsletter or publications
STUART	22/01/07	Informal interview	Developing rapport Study explanation Discuss consent Key thread: Very strong family network & support Impact of epilepsy on his career as an engineer	55	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	14/02/07	Formal interview	Onset & teenage experiences Impact of epilepsy on working life – non-disclosure to employers but work colleagues very supportive. Strong marriage with positive support from wife/children	95	Formal interview tape recorded and supplemented by notes Happy to review transcript interested in receiving study newsletters and publications
	19/03/07	Copy of interview transcript;	N/A	N/A	Stuart telephoned and suggested we

		Newsletters issues 1 & 2 sent via post			meet again to talk through the transcript. He had recently fallen and fractured his collar bone. He felt it would be easier to talk than to write down his comments/thoughts
	28/03/07	Informal meeting to review transcript/emerging themes	Stuart was unhappy with the number of acronyms and slang words that appeared in his transcript. He felt it made him appear uneducated. I explained that his quotes could be 'tidied up' if this is what he preferred. Transcript / themes validated and he spoke further about the support he received from family and friends, especially since his recent fall. Excited as his son will shortly be returning from IRAC [he showed me a video recording of a recent news item in which his son had appeared on screen]	65	Observational data / contextual descriptions recorded by hand written fieldnotes Said he and his wife would be interested in receiving a copy of the published paper
	30/03/07	Copy of published paper sent via post	Jacoby, A., Snape, D., Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurology. 4:171-78	N/A	Telephone call from Stuart thanking me for copy of published paper which he said he had enjoyed reading
	03/12/07	Copy of Newsletter issue 3 sent via post	N/A	N/A	No response
FRAN	29/01/07	Informal interview	Developing rapport Study explanation Discuss consent Key thread: Anxiety and shame associated with having epilepsy Fear of others knowing Feels she copes on her own as husband works away a lot	90	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	20/02/07	Formal interview	Onset & childhood experiences Impact of epilepsy on marriage and childcare Lack of medical understanding Initial non-disclosure to husband; children still unaware of Fran's epilepsy Feels stigmatised, fear of sz's Feels stuck – no way forward	180	Formal interview tape recorded and supplemented by notes Happy to review transcript interested in receiving study newsletters Interested in speaking with clinical psychologist – contact details left with Fran
	01/03/07	Copy of interview transcript; Newsletters issues 1 & 2 sent via post	Telephone follow-up to discuss transcript – Fran was happy with content and themes. Expressed further concern about her boys and her fear of them discovering she had epilepsy.	40	As Fran hadn't done so, I suggested she contact the clinical psychologist linked to the study as he may be able to offer her support with the process of disclosing her condition to her children
	03/12/07	Copy of Newsletter issue 3 sent via post	N/A	N/A	No response
LARRY	05/02/07	Informal interview	Developing rapport Study explanation Discuss consent Key thread: *"Horrible marriage"* Much happy now that he has the support of community living Can cope with having epilepsy better	50	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	19/02/07	Formal interview	Onset & childhood experiences Impact of epilepsy on working life & marriage Lack of support from children Community living very supportive More positive outlook on life	90	Formal interview tape recorded and supplemented by notes Does not wish review transcript or to receive study newsletter or publications

			Larry has made friends		
MARTIN	06/02/02	Informal interview	Developing rapport Study explanation Discuss consent Key thread: Difference in lifestyle – past history as a career soldier v current situation with epilepsy	45	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	27/02/07	Formal interview	Onset & army experiences Impact of army life and epilepsy on working life & marriages Difficult to cope in 'civvy street' Current wife and neighbours very supportive Only identifies short term goals	125	Formal interview tape recorded and supplemented by notes Does not wish review transcript or to receive study newsletter or publications
CHARLES	27/02/07	Informal interview	Developing rapport Study explanation Discuss consent Key thread: Loss of navel career & perceived unfair dismissal	60	Observational data recorded by hand written fieldnotes / contextual descriptions used to inform future discussion
	08/03/07	Formal interview	Onset & treatment Impact of epilepsy on career Issues around having epilepsy and finding a job in 'civvy street' Disruption to lifestyle and navel friendships New interests identified – football coach and player Recognises support of wife but feels guilty that she does so much for him Now has P/T job with potential for promotion	130	Formal interview tape recorded and supplemented by notes Interested in receiving study newsletter but does not want to review transcript
	12/03/07	Copy of Newsletter issue 3 sent via post	N/A	N/A	No response